Health Canada Santé Canada

Evaluation Group **Groupe de l'évaluation**

Strategic Planning and Review Directorate **Direction de la planification stratégique et de l'examen**

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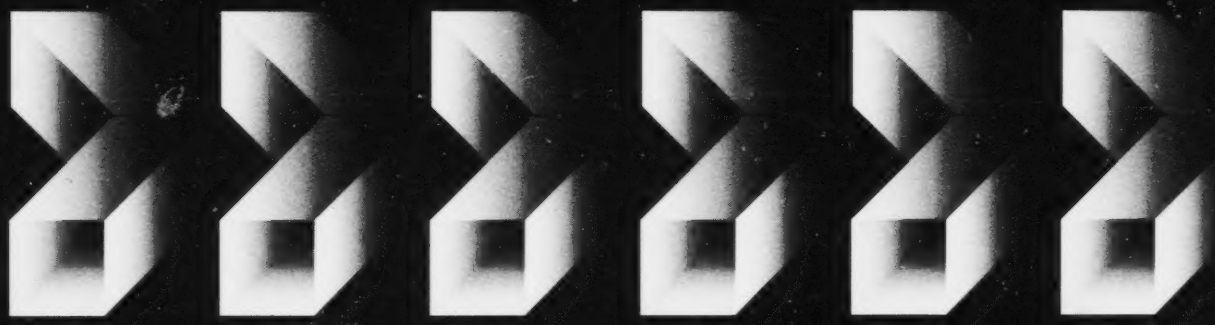

EXECUTIVE SUMMARY

MID-TERM REVIEW

NATIONAL AIDS STRATEGY - PHASE II

March 15, 1996

Canada

MISSION STATEMENT

The Evaluation Group helps Health Canada serve Canadians better by providing objective information and advice about the effectiveness of departmental activities and services.

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EXECUTIVE SUMMARY
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FOREWORD

The Mid-term Review collected information during the Fall of 1995, a time when significant changes were taking place within the Department and Health Promotion and Programs Branch. The climate of rapid change has persisted until now, and it is expected to continue into the future. As a consequence, some of the organizations and situations referred to in the report may have changed. For example, the functions of the National AIDS Secretariat, which was established to coordinate the Strategy, have now been assumed by the HIV/AIDS Policy and Coordination Office (HAPCO). Thus, findings and observations in the Mid-term Review that applied to the Secretariat and its functions should now be related to HAPCO.

The purpose of the Mid-Term Review was **not** to assess the success of the Strategy - the final evaluation will do that. The Mid-term Review was mandated to examine whether all the elements necessary for the Strategy to succeed were in place and functioning effectively. It was to ascertain if information needed to evaluate its success was available or being collected. It was to collect information about the Strategy from a cross-section of key non-government stakeholders to be used as a baseline for the final evaluation. Finally, it was to determine whether any mid-course corrections were necessary. The findings and recommendations of the Mid-term Review are intended to provide information to inform the government in designing an approach to the on-going issues and changes the Strategy faces in its remaining years.

Although the Mid-term Review does not assess the success of the Strategy, provision was made in designing NAS II, to report on achievements. The National AIDS Secretariat, and now the HIV/AIDS Policy, Coordination and Programs Division, prepare Annual Progress Reports to document the achievements of the Strategy. The Mid-term Review is complemented by the recently released National AIDS Strategy, Phase II Progress Report 3, 1995-96. It is suggested that this report be read as an essential complement to this review, which is focused on mid-term corrections.

EXECUTIVE SUMMARY
NATIONAL AIDS STRATEGY
PHASE II MID-TERM REVIEW

1. INTRODUCTION

The National AIDS Strategy is a collective effort involving more than a dozen separate federal government responsibility centres working in concert with other levels of government, non-government organizations and the private sector to respond to the HIV/AIDS epidemic. Phase II of the National AIDS Strategy (NAS II), a continuation of Canada's initial response to the epidemic, was approved by Cabinet in March 1993. NAS II received a budget of more than $200 million to be spent over five years beginning in April 1993 and scheduled to sunset March 31, 1998.

Health Canada undertook to conduct a Mid-term Review in 1995/96 to assess if the Strategy was on target and to identify if any mid-course corrections were required. It represents a stock-taking of whether essential elements and processes are in place, rather than an assessment of achievements and success to this point. The focus of the Mid-term Review is on federal government components of the Strategy. Its orientation is primarily "top-down" instead of on the individual programs.

The Terms of Reference state that the Mid-term Review will:

a) examine the extent to which structures, mechanisms, and processes that are critical for the success of NAS II have been established and are being maintained and used effectively;

b) assess the extent to which information and statistics that will be necessary to evaluate the National AIDS Strategy are available, or are being collected and will be available for the evaluation. This will include an assessment of the quality, dissemination, usefulness and use of the information; and

c) develop a panel study of non-government stakeholders to obtain information on the responsiveness of NAS II for both the Mid-term Review, and for use as a benchmark in the final evaluation to examine changes over time.

The Mid-term Review comprised three separate studies:

1. an internal study, focusing primarily on Health Canada, reviewed program files; consulted selected federal officials in Ottawa and in Health Canada's regional offices, and selected provincial officials; and examined statistical and management information;

2. a parallel internal study conducted by Correctional Service Canada (CSC) that involved document review and consultations with key officials in that organization; and

3. a telephone survey conducted to obtain the views and perceptions of a cross-section of non-government stakeholders. This survey will serve as the first wave of a longitudinal *panel study*, which will be repeated at the time of the final evaluation to assess the responsiveness of the Strategy and what changes have taken place over time.

Each of the three studies focused on four common issues — **coordination**, **implementation**, **balance** and **information** — that will affect the ultimate success of the Strategy. This report describes the Mid-term Review and presents its findings drawn from all three studies.

2. FINDINGS AND RECOMMENDATIONS

A. COORDINATION

Overall responsibility to coordinate NAS II and to oversee its implementation rests with the National HIV/AIDS Secretariat. It is responsible for facilitating the planning of the Strategy, and ensuring that all policies and programs are consistent with the major goals of NAS II. The Secretariat does not have financial authority over the components within the Strategy, but it maintains a process for financial accountability including quarterly status reporting, periodic review of annual budgets and expenditures, and coordinating adjustments across the Strategy.

Because the National AIDS Strategy works through networks of collaborative relationships with an array of partners, effective coordination is vital. The Mid-term Review looked at coordination from several perspectives: internally within the Strategy; between the Strategy and other federal agencies; between the Strategy and non-government partners and clients; and inter-governmental (federal/provincial/territorial) and international coordination.

The Mid-term Review examined coordination at both a Strategy-wide level, and at the level of components. This included reviewing what coordinating mechanisms or structures the National AIDS Strategy, Phase II used, and how well they were operating.

At the Strategy-wide level, most of the necessary coordinating mechanisms are in place. The National Advisory Committee on AIDS and the Federal/Provincial/Territorial Advisory Committee on HIV/AIDS represent vehicles for policy input and information sharing on national issues and priorities. The National AIDS Secretariat's liaison with the "National Partners" forum provides a linkage with the non-government sector. However, there has been uncertainty with regard to international coordination, although steps have been initiated to clarify roles in this arena.

RECOMMENDATION 1.

The National AIDS Secretariat should improve its international coordination at a global level by identifying, in consultation with the International Affairs Directorate, specific responsibility for this activity within the Department, and by dedicating adequate Secretariat resources for this function.

Specific activities that the Secretariat should carry out include:

a) developing an active and comprehensive inventory of all international HIV/AIDS bodies and initiatives in which Canada is or should be involved, and identifying for each the liaison person or office of primary interest; and

b) establishing a process, in collaboration with the International Affairs Directorate and other agencies as appropriate, to develop a Canadian Strategy (objectives, priorities, resource levels, action plan and timeliness) that describes Canada's role and contributions in HIV/AIDS in the international arena.

Although steps have been taken to clarify roles for formal international coordination, little evidence was found of international coordination at the program or working level, with the notable exception of LCDC, which acts as a WHO collaborating centre for AIDS Research. Although individual program managers may attend conferences in their respective areas of activity, there was no evidence of mechanisms to routinely exchange information with other countries so that NAS II research, model building and resource development activities could dovetail with, build upon, or complement activities in other nations.

RECOMMENDATION 2.

The National AIDS Secretariat should improve international coordination on a sectoral basis by establishing mechanisms and assigning responsibilities for monitoring international activities in:

a) **the full spectrum of epidemiological, medical, clinical and behavioural HIV/AIDS research;**
b) **development and use of education/prevention programs, activities, resources and materials; and**
c) **the development and evaluation of alternative models of delivery of care, treatment and support.**

Establishing mechanisms for sector-specific international coordination will allow Canada to ensure our research and other developmental activities complement and build upon the efforts elsewhere, and that we do not reinvent the wheel when we can capitalize on the work of others. It will also enable the Strategy to share with others what has been done and learned in Canada, and to develop programs and priorities with the benefit of knowledge about what has been done, and is being done, elsewhere.

National coordination mechanisms are functioning effectively, but more active collaboration will be needed to chart a course for transitions when NAS II ends. Although there are indications that the HIV/AIDS epidemic may be levelling off, it is estimated that overall there are between 2500 and 3000 new cases of HIV infection each year in Canada. The rates of infections among two at-risk populations for which the federal government has responsibility, Aboriginals and inmates of federal corrections institutions, are increasing. Further, because the latency period before the disease develops into AIDS can be 10 years or longer, there will be a continuing need for programs and services after the end of Phase II of the Strategy. Quite simply, the epidemic will not conveniently disappear when NAS II funding ends.

Given the fiscal climate facing all governments, it will be necessary to review and decide what must be done and who is best positioned to do it. For example, although federal education and prevention programs have yielded benefits, many respondents felt provincial governments should be picking up such responsibilities. Development of community-based capabilities was identified as another area in which the provinces could assume responsibility. Review of responsibilities and capabilities may require additional effort to ensure that the necessary time and energy is directed and devoted to mid-range national planning.

RECOMMENDATION 3.

Federal-provincial collaboration should be intensified during the remainder of NAS II to ensure there is adequate planning for and coordination of any transitions that might arise from post-Phase II changes in federal HIV/AIDS programming.

The Department and other federal participants in NAS II may need guidance regarding how the federal government wants to manage the end of Phase II, and what the federal role would be thereafter. Preparation of a discussion paper would be one avenue of ensuring that this issue is on the agenda early enough to allow the federal government to take proactive measures.

Although there are mechanisms are in place, there is need to enhance internal coordination and collaboration. The four existing departmental committees and the manner in which they are utilized require improvement. Attendance at departmental committees established to coordinate activities is uneven. For the most part, committee meetings are restricted to information sharing, with little emphasis on overall strategic planning in resource allocation or long-term programming. There is duplication of agenda items and membership on some committees. Improvements can be achieved by streamlining the committee structure.

RECOMMENDATION 4.

The National AIDS Secretariat should redesign the departmental coordinating committee structure as follows:

a) recast the function of the AIDS Coordinators Committee to serve as a collaborative Strategy-wide planning, monitoring and policy-making body, and concurrently adopt or develop other methods and mechanisms for information sharing;

b) reconfigure the AIDS Research Committee into a small multi-Branch working group to coordinate all HIV/AIDS research carried out and/or funded by the Government of Canada, and to report regularly to the AIDS Coordinators Committee;

c) **discontinue the Working Committee on Women and AIDS, and, to ensure that adequate consideration is given to this area, identify women's issues as an obligatory agenda items on a quarterly basis, for the AIDS Coordinators Committee. Special project teams, including branch officials and representatives of external stakeholders if necessary, can be struck as and when the need arises to work on specific issues, to report back to the AIDS Coordinators Committee.**

The organizational structure within the Strategy has not been stable. The reporting relationship of the Secretariat has changed twice, shifting from the Associate Deputy Minister to the Assistant Deputy Minister of the Health Programs and Promotion Branch, and then to the Population Health Directorate within that Branch. At present, there is no designated decision-maker or body with authority to approve decisions requiring reallocations of resources between branches. This hinders the Secretariat's ability to influence the overall balance of activities and programs, and raises questions about what level of coordination and responsiveness can be reasonably expected of it.

RECOMMENDATION 5.

The Department should review the mandate of the National AIDS Secretariat and strengthen its authority to enable it to more effectively guide and coordinate the Strategy.

In the immediate term, the National HIV/AIDS Secretariat should be given the responsibility, authority and resources to regularly monitor expenditures, program plans and monetary requirements of the participating responsibility centres, and to reallocate funds from programs with underutilized budgets.

NAS II is but one of a number of multi-component endeavours, such as the Child Development Initiative and Canada's Drug Strategy, of which Health Canada is the lead department, and horizontal approaches are becoming more common. The Mid-term Reviews and evaluations of these undertakings have identified certain common difficulties in their coordination and leadership.

In the longer term, and with more general application, the Department should develop a framework that identifies conditions that are prerequisites for success of multi-component strategies and initiatives, to be used as a checklist in designing multi-program initiatives. These would include identifying:

- the specific planning, implementation, monitoring, policy making, and resource allocation responsibilities of the organizational unit charged with coordinating the Strategy;
- the requisite authority to discharge the responsibilities;
- the resource allocations to be applied to these functions; and
- the specific accountability relationships and reporting requirements of all participating organizations.

There is fairly widespread concern among both government officials and external stakeholders about the National AIDS Secretariat's effectiveness and leadership in coordination. This stems in part from changes in its reporting relationships (with an attendant diminishment of perceived "clout"), and its lack of authority to actively manage NAS II resources. It also derives from frequent staff turnover and failure to maintain a full compliment of senior level staff. The National AIDS Secretariat, which is responsible for overall coordination of NAS II, lapsed one sixth of its budget in the first year, and one quarter of its budget the second year. This was attributed mainly to the fact that the Secretariat is operating at 75 percent of its allocated staff complement, which impacts on its ability to perform its coordinating role.

RECOMMENDATION 6.

> **The National AIDS Secretariat should maintain its human resources at the level and capacity needed to carry out all necessary coordination activities. The coordination function should be staffed by officers with knowledge of the departmental responsibility centres and staff, and have coordination activities as their primary responsibility.**

In several areas, there is need for more collaboration between participating responsibility centres to share and exchange information. Although bilateral linkages exist between some programs and in some regions, and both the Epidemiology and Drugs Research programs regularly disseminate information to all the other players, collaboration between most components is notably absent.

In particular, there is need for more information exchange between the "science" components and the community-oriented programs.

RECOMMENDATION 7.

> **All participating programs should more actively seek out information from, and share information with other responsibility centres participating in NAS II. One means of informing others is for each program to prepare and distribute its annual work plans and priorities and annual reports or inventories of projects underway. The Secretariat should oversee this activity, and prepare an annual inventory of such plans and reports to coordinate this activity.**

The Strategy's national non-government partners are intended to serve as conduits between the federal government and the broader HIV/AIDS community. Most non-governmental stakeholders contacted during the mid-term review were familiar with NAS II and the information resources available through the Strategy. However, about one-fifth of them had limited information about the Strategy and the resources it has generated. Moreover, half of the stakeholders indicated that they felt unable to effectively provide input to the Strategy.

RECOMMENDATION 8.

> **The National AIDS Secretariat should review the coordination mechanisms of its major non-governmental partners to ensure there is effective communication, collaboration and information dissemination with the broader AIDS community.**

B. IMPLEMENTATION

On the whole, there is little criticism with the implementation of NAS II. Most programs feel they have made positive strides in responding to the epidemic. Unfortunately, in most areas there is a dearth of "hard" information to document what has been done, and with what effect. There is little Strategy-wide descriptive information. Financial information reveals some shifts and variances between what had been planned and what was actually done. Of particular interest, resources for coordination have lapsed, indicating that less was done than planned. This is noteworthy in view of the identified need for improved coordination.

Scarcity of management information in most areas points to a significant deficiency with regard to the objective of monitoring the performance and effectiveness of NAS II. Although some components are developing information systems on the management and operation of their programs, progress is slow. There is a need to ensure it will be possible to "roll up" information to provide a Strategy-wide picture of what is being done, where, for whom, and to what end.

RECOMMENDATION 9.

> **All programs should give high priority to completing the development and implementation of information systems to describe planned activities and report on projects implemented and outputs generated. The National AIDS Secretariat should prepare annual Strategy-wide "roll-ups" of projects and activities to report on the implementation of NAS II, and identify programs whose available information is deficient.**

Stakeholders are generally satisfied with implementation of NAS II. Eighty percent indicated that implementation of NAS II had helped them conduct a desired range of activities. They did, however, identify areas in which improvements in balance can be made.

C. BALANCE

Initial allocations of resources among the major activity areas of the NAS II were decided when the proposal for Phase II was prepared more than 3 years ago. The epidemic has continued to evolve since then, and the capacities and needs of the various players have changed with time and experience. The Mid-term Review identified two gaps — a need for more culturally sensitive programs and services for First Nations communities, and the need to bridge the gulf between science and programs. A need to review the alignment of services and responsibilities of the federal and provincial governments was also noted.

RECOMMENDATION 10.

> **As part of preparation of a Strategy-wide plan for the remainder of Phase II, the National AIDS Secretariat should undertake a review of allocations and utilization of Strategy funds, and, in consultation with the programs and other major participants, identify mid-course corrections, together with their relative priorities.**

Although circumstances compelled the federal government to mount a comprehensive National AIDS Strategy, some aspects of NAS II are in areas recognized as provincial responsibilities. Since the Strategy was first implemented, provinces have developed capabilities in the HIV/AIDS field. Public accountability and the current economic climate and dictate that governments take measures to use resources to best advantage. The remainder of Phase II of the National AIDS Strategy provides an opportunity for both levels of government to review their collective efforts in response to the HIV/AIDS epidemic, and to plan the future in a manner that respects jurisdictional responsibilities, capacities, and is sensitive to the need to provide comparable services to all Canadians. In the interests of serving the Canadian population, the transition to post NAS II should be seamless, with no abrupt discontinuities or disruptions of programs and services.

RECOMMENDATION 11.

The National AIDS Secretariat should develop a transition plan in consultation with provincial HIV/AIDS officials on how to collectively optimize the division of effort, expertise and shrinking resources.

There are widely divergent views regarding research in HIV/AIDS. There is a lack of coherence regarding whether too much or too little research is being done, whether the right kind of research is being done, and what value is derived from it. There is a need to review research activities and come up with overall framework and priorities for federally funded HIV/AIDS research, from both a national and a global perspective. This need is not unique to HIV/AIDS research, but is common to the broader issue of research conducted and supported by Health Canada.

Enough time has lapsed that HIV/AIDS research programs should have generated sufficient findings to allow identifying over-studied areas, and areas where promising developments are taking place. It should also be possible to identify voids in research. These may be areas where Canadian expertise and attention could be focused to increase the odds that Canadian research funding will contribute to finding better vaccines and therapies, and developing better models of care, treatment and support.

RECOMMENDATION 12.

Each participating program that conducts, funds or uses research should dedicate resources and assign responsibility to monitor what is happening nationally and globally in relevant research areas. The Secretariat should establish a mechanism for programs to periodically share information with other NAS II participants about where there have been successes that can be capitalized on, and where promising research is being done.

RECOMMENDATION 13.

> **The National AIDS Secretariat should coordinate a national conference involving selected federal and provincial HIV/AIDS research funders; policy and decision makers; experts and outside advisors; and researchers from the behavioural, medical, clinical, and epidemiological fields to identify immediate and medium-term HIV/AIDS research priorities, and develop a framework for Strategy-wide research funding, reporting, dissemination and use of results.**

D. INFORMATION

The information reviewed in the Mid-term Review indicates it would be difficult at this time to evaluate the performance and success of NAS II. Current monitoring activities do not provide a global picture of the Strategy's activities. Departmental financial and project management information systems are not used by many programs because the information provided by these systems is frequently faulty and not timely. Many programs have opted to develop alternative tracking systems tailored to their needs, but these are still in their infancy and bugs are being worked out. It is not possible to consolidate information from these tailor-made systems to produce standard Strategy-wide reports.

There is need for management information on inputs, outputs and impacts that is amenable to making Strategy-wide comparisons and preparing roll-ups. This includes information on each programs's plans, priorities and program implementation, (what, where, when, how, for whom, how much), as well as information on what products and resources have been produced with NAS II funding, what use has been made of them, and what impacts they have had. While some programs have or are developing useful information, more remains to be done to allow examining the performance and success of NAS II in the final evaluation scheduled to be completed by September 1997.

RECOMMENDATION 14.

> **The National AIDS Secretariat should require all participating programs to report what management/statistical information they currently collect and what information systems they are currently developing, and establish a central inventory of HIV/AIDS information systems, to be updated semi-annually.**

RECOMMENDATION 15.

> **Programs that do not have fully operational management information systems capable of producing satisfactory information for Strategy-wide comparisons, roll-ups or evaluation purposes should adopt or clone an existing system developed by a comparable program (e.g. ACAP for projects).**

It is difficult to determine whether the efforts under the Strategy are unfolding as had been planned, or whether federal activities are having an impact. Programs do not do a good job of monitoring impacts. Self evaluations by stakeholders and NAS II clients have yielded mixed benefits. Some components are making efforts to develop evaluation indicators and information systems. Development of tools and skills to assist them are needed.

More information is needed about what is being done, achieved and/or produced with NAS II funds provided to non-governmental partners. It is needed to be able to demonstrate what benefits have accrued, to identify areas of need and priority, and to assess the success of Phase II of the national AIDS Strategy.

RECOMMENDATION 16.

> **The National AIDS Secretariat should develop standard or model reporting formats, include reporting requirements on what has been done, what products have been generated, and what results have been achieved, to be included as part of all contribution agreements for NAS funding. It should be a condition of all contribution agreements that funding will be contingent upon receipt of the specified report.**

Inventories describing what products, resources and information have been produced by NAS II funding recipients in each program would allow officials to better screen funding proposals for potential duplication, and to direct funding applicants to other NGO's and community groups who have already developed products. If these inventories were disseminated or accessible electronically, they could serve as a resource to the broader HIV/AIDS community.

RECOMMENDATION 17.

> **The National AIDS Secretariat should develop standard or model inventories of NAS II products (including "lay language" research summaries identifying potential applications) produced by external funding recipients. NAS II programs should disseminate these inventories to other governments and the stakeholders via the CPHA Clearinghouse and/or the Internet.**

The epidemiological data collected by NAS II through the National AIDS Case Reporting Surveillance System is generally acknowledged as being high quality, reliable and standardized. However, AIDS data report on the disease only when it has progressed to a point that a number of symptoms are evident. Many years can pass before the disease progresses to the point that AIDS is diagnosed and must be reported. AIDS statistics therefore have a retrospective character that diminishes their usefulness in monitoring the spread of HIV, and identifying risk factors and trends in a timely enough manner to guide programs.

In comparison, HIV data, which are not mandatory to report, are based on the initial evidence that the person has contracted the HIV virus. There is broad consensus that more effort is needed to design and implement a national HIV data base. As a national agency, the Laboratory Centre for Disease Control (LCDC) is regarded as best situated to lead in this area.

There is an urgent need to improve the information available to target, manage and evaluate the National AIDS Strategy and many of the activities that are part of it. One important requirement is for up-to-date epidemiological information about the spread of the HIV infection (where, who, how much, when, and how), which also allows assessing how effective various NAS II efforts have been. At this time the Department must use whatever provincial HIV epidemiological information is available to identify priorities, target efforts, and monitor effectiveness.

RECOMMENDATION 18.

> **The HIV/AIDS Epidemiology Division should place high priority on establishing a national HIV data base, to supplement the AIDS data and to replace AIDS data as the primary national statistics to monitor the epidemic and guide planning of national programs in response to the epidemic.**

RECOMMENDATION 19.

> **The Department should initiate steps to include HIV as a "reportable" communicable disease comparable to STDs.**

RECOMMENDATION 20.

> **The Strategy, especially LCDC and Correctional Service Canada (CSC), should improve the quality of detailed epidemiological information about HIV and AIDS in at risk groups such as Aboriginals, inmates and females to be better able to monitor trends in the epidemic among these sub-populations.**

It was noted that media articles about HIV/AIDS are frequently inaccurate. This is of interest in light of the fact that epidemiological statistics are made public on a regular basis. However, the statistics presented in various reports differ, which may lead to confusion on the part of the media and the public, and adversely affect the credibility of the Department. There is need to better inform the public to increase its knowledge and understanding about the disease.

RECOMMENDATION 21.

The HIV/AIDS Epidemiology Division should make its *AIDS In Canada* quarterly surveillance report more "user friendly" by adding an introductory section explaining in lay language the difference between HIV and AIDS and why LCDC reports AIDS statistics. The report should clarify that the incidence statistics are cumulative counts, and that the number of Canadians with AIDS is the difference between the cumulative incidence counts and the cumulative deaths from AIDS.

Little use appears to be made of results of research funded by the National Health Research Development Program (NHRDP) or the Medical Research Council (MRC). This reflects inadequate linkages between the research community and program managers and policy makers. Program managers are uncertain what research is being produced, and are unable to influence the focus of research. The Mid-term Review found that although need for more attention to research into risk behaviours in high risk populations was identified, there is no input into the selection of research projects by "non-scientist" program mangers. A two-pronged effort, consisting of improving the dissemination of information about proposed and completed research, and involving policy-makers and program managers in decisions about research priorities and project selection will be needed to bridge the gulf between science and programs.

RECOMMENDATION 22.

The programs within the National AIDS Strategy, Phase II that conduct or fund research should prepare a collective annual summary describing the HIV/AIDS research proposed, funded, underway and completed, and distribute it to all HIV/AIDS programs and the Secretariat.

RECOMMENDATION 23.

The Secretariat should review, with the research components of NAS II, the processes for setting HIV/AIDS research priorities and selecting research proposals to ensure that the input of program managers and policy makers is reflected in selecting what research is done.

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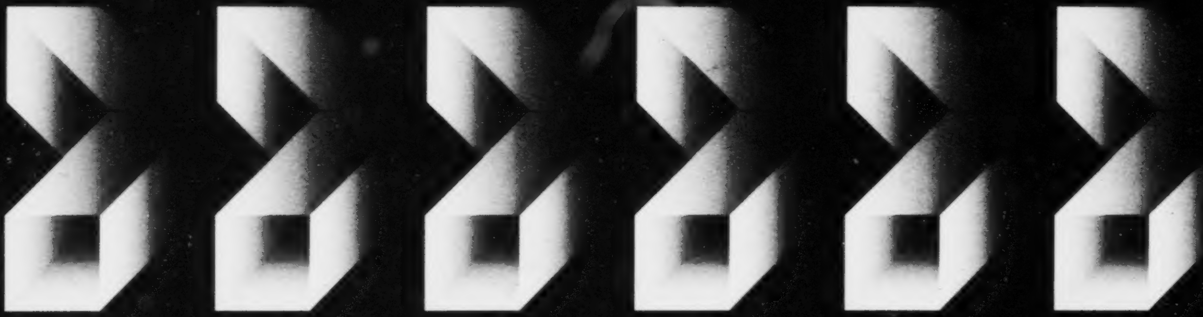

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March 15, 1996

This report was originally prepared in English and translated into French. Although the quality of the translation of this document has been reviewed, because of the use of technical/methodological terminology, please note that in the event of any difference of interpretation in the two languages, the English language version should take precedence.

Credits

Leo Lehtiniemi, Evaluation Group, Strategic Planning and Evaluation Division, Health Canada, was the project manager and author of the report on the Mid-term Review.

Gord Farrell, Accountability and Performance Measurement Sector, Correctional Service Canada, conducted the CSC parallel study and prepared the draft report on the CSC Interim Review.

Holly Flowers, Accountability and Performance Measurement Sector, Correctional Service Canada, managed the internal review of the CSC parallel study draft report and prepared the revised report on the CSC HIV/AIDS Mid-term Review.

Nina Arron, National AIDS Secretariat, provided coordination and liaison with participating responsibility centres.

T.K. Gussman Associates Inc., Consultants, conducted the Health Canada internal review and interviewed federal and provincial officials.

Brighton Research, Consultants, designed and carried out the initial wave of the panel study of non-government stakeholders

Note: The assistance and cooperation of the managers, staff and regional officials of all the responsibility centres that participate in the National AIDS Strategy in Health Canada, the Medical Research Council, Correctional Service Canada, and provincial government agencies is gratefully acknowledged.

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FOREWORD

The Mid-term Review collected information during the Fall of 1995, a time when significant changes were taking place within the Department and Health Promotion and Programs Branch. The climate of rapid change has persisted until now, and it is expected to continue into the future. As a consequence, some of the organizations and situations referred to in the report may have changed. For example, the functions of the National AIDS Secretariat, which was established to coordinate the Strategy, have now been assumed by the HIV/AIDS Policy and Coordination Office (HAPCO). Thus, findings and observations in the Mid-term Review that applied to the Secretariat and its functions should now be related to HAPCO.

The purpose of the Mid-Term Review was **not** to assess the success of the Strategy - the final evaluation will do that. The Mid-term Review was mandated to examine whether all the elements necessary for the Strategy to succeed were in place and functioning effectively. It was to ascertain if information needed to evaluate its success was available or being collected. It was to collect information about the Strategy from a cross-section of key non-government stakeholders to be used as a baseline for the final evaluation. Finally, it was to determine whether any mid-course corrections were necessary. The findings and recommendations of the Mid-term Review are intended to provide information to inform the government in designing an approach to the on-going issues and changes the Strategy faces in its remaining years.

Although the Mid-term Review does not assess the success of the Strategy, provision was made in designing NAS II, to report on achievements. The National AIDS Secretariat, and now the HIV/AIDS Policy, Coordination and Programs Division, prepare Annual Progress Reports to document the achievements of the Strategy. The Mid-term Review is complemented by the recently released National AIDS Strategy, Phase II Progress Report 3, 1995-96. It is suggested that this report be read as an essential complement to this review, which is focused on mid-term corrections.

NATIONAL AIDS STRATEGY PHASE II MID-TERM REVIEW

A. INTRODUCTION

In March 1993, Cabinet approved Phase II of the National AIDS Strategy (NAS II). The Strategy is a collective effort involving more than a dozen separate federal government responsibility centres working in concert to respond to the HIV/AIDS epidemic. It also involves extensive cooperation with other levels of government, non-government organizations and the private sector. NAS II received a budget of more than $200 million to be spent over five years beginning in April 1993 and scheduled to sunset March 31, 1998.

The primary objectives of NAS II include: working to stop the spread of HIV; providing care, treatment and support for persons living with HIV/AIDS; and searching for effective vaccines, drugs and therapies. An additional goal emphasizes evaluating all programs and projects to ensure that each is achieving its goals and managing its resources effectively.

As a condition of approving funding for NAS II, Treasury Board asked that the Strategy be carefully monitored, both to evaluate its effectiveness and to identify any new or emerging issues that should be reflected in it. In that regard, an evaluation framework, which identifies questions and indicators to assess the success of both the Strategy as a whole and each of its constituent responsibility centres, was completed in 1994. Further, Health Canada made a commitment to conduct a Mid-term Review in 1995/96 to assess if the Strategy was on target and to identify if any mid-course corrections were required. Terms of Reference for the Mid-term Review were approved in July 1995.

This report describes the Mid-term Review and presents its findings.

A.1. BACKGROUND

In the late 1980s, the government of Canada initiated a National AIDS Strategy in response to the growing epidemic of HIV/AIDS. In 1989 there were 1254 new cases of AIDS, and the total number of AIDS cases reported in Canada since the first case in 1979 had risen to 4426. The Department of National Health and Welfare consulted across Canada with community-based groups, health care providers, researchers, provincial governments, municipal governments, public health professionals and others involved in HIV/AIDS programs and activities. The purpose was to mobilize all affected sectors of the nation, because it was recognized that the disease would have impacts on all segments of society. The approach was to develop an infrastructure of partnerships, because no single sector could succeed by itself, and collective action would be needed to respond.

The documents resulting from these consultations set out common goals and directions, and described the steps the federal government would take to work with its partners to achieve those goals. The initial Strategy had three objectives: stopping the spread of HIV; providing care, treatment and support for people living with HIV/AIDS; and searching for effective vaccines, drugs and therapies. Three years after the start of the initial Strategy, the federal government once again talked with its partners - to assess the Strategy, to note the achievements and to set the direction for the next five years.

A.1.1. THE NATIONAL AIDS STRATEGY, PHASE II

Phase II of the National AIDS Strategy is a continuation of Canada's initial response to the epidemic. Having developed an infrastructure in all sectors during phase I, NAS II continued to encourage more collaboration and to build closer links with the public and private sectors.

At the federal level, most of the organizations participating in the Strategy are part of Health Canada. The *National AIDS Secretariat* is responsible for overall coordination of the NAS II. It arranges regular meetings of federal AIDS program coordinators, monitors the implementation of the Strategy, and provides support to high level national committees that advise the Minister of Health and the federal and provincial deputy ministers of Health. It is also active in coordination at the international level. Initially, the National AIDS Secretariat reported to the Associate Deputy Minister of Health and Welfare Canada; it is now part of the Health Programs and Promotion Branch.

There are four other components of NAS II in the **Health Programs and Promotion Branch**. The *AIDS Community Action Program*, the *AIDS Education and Prevention Unit*, and the *AIDS Care Treatment and Support Unit* are dedicated to AIDS-related activities. These components of the Strategy support community-based and national organizations develop programs, resources and service delivery models. The *National Health Research and Development Program*, commonly known as NHRDP, supports AIDS-related research and career training as part of its broader extramural research funding activities.

The **Health Protection Branch** of Health Canada includes five responsibility centres that participate in the National AIDS Strategy, Phase II. Two of these, the *Division of HIV/AIDS Epidemiology* and the *Bureau of HIV/AIDS Laboratories and Research* are part of the Laboratory Centre for Disease Control (LCDC). LCDC also contains a Bureau of External Cooperation responsible for maintaining contact with comparable organizations in other countries.

Three of the Health Protection Branch responsibility centres involved in NAS II are in the Drugs Directorate. The *Bureau for Human Prescription Drugs* regulates applications for pharmaceutical drugs, including those that might be used for HIV/AIDS. It also reviews protocols for HIV clinical trials, and under special circumstances (on a case-by-case basis) authorizes compassionate release of some drugs for physicians to treat patients with HIV/AIDS. The *Bureau of Drug Research* conducts in vitro laboratory studies of the effectiveness of drugs and combination of drugs in controlling HIV/AIDS. The *Bureau of Biologics* regulates biologically-based drugs, and the Red Cross's use of test kits for the safety of blood. (At the time of the Mid-term Review, the Bureau of Biologics was involved in the Royal Commission on the Safety of Blood and Blood Products. Accordingly, examination of the Bureau's activities as part of the Mid-term Review was deferred.)

The *First Nations and Inuit Health Programs Directorate* of the **Medical Services Branch** (MSB) is responsible for HIV/AIDS activities and services for First Nations and Inuit under MSB's mandate. MSB provides community-based funding to support education and prevention programming suitable to the unique needs of the Aboriginal communities for which it is responsible.

NAS II includes two organizations external to Health Canada. The **Medical Research Council** (MRC), an autonomous body created under the Medical Research Council Act, is involved with the NHRDP in a joint program to fund applied HIV/AIDS research and career development. It also has a separate and independent program to fund basic research and career development related to HIV/AIDS. The other organization, **Correctional Service Canada** (CSC), is responsible for HIV/AIDS programs for federal corrections inmates and staff.

The federal government components of NAS II are listed in Table 1. A more detailed description of their activities can be found in the Evaluation Framework report. (It should be noted that some organizations' names changed after the Framework was prepared, and others changed during the Mid-term Review.)

There are also many non-federal participants in the National AIDS Strategy, Phase II. All of the provinces are involved with many of the federal components. For example, provinces participate on a Federal/Provincial/Territorial committee on HIV/AIDS, cooperate in epidemiological surveillance, and often coordinate their program efforts with federal activities.

Experts from diverse non-government backgrounds sit on a National Advisory Committee on HIV/AIDS constituted to provide independent advice to the federal Minister of Health. The five major non-government organizations involved in HIV/AIDS (i.e. the Canadian AIDS Society, the Canadian Association of HIV Research, the Canadian Foundation for AIDS Research, the Canadian Hemophilia Society, and the Canadian Public Health Association) function as national forum to promote, enhance and encourage collaborative initiatives and partnerships in the implementation of NAS II.

TABLE 1
NAS II FEDERAL GOVERNMENT COMPONENTS

HEALTH PROGRAMS AND PROMOTION BRANCH

- National AIDS Secretariat *
- AIDS Community Action Program (ACAP)
- AIDS Education and Prevention Unit (AEPU)
- AIDS Care, Treatment and Support Unit (ACTSU)
- National Health Research and Development Program (NHRDP)

HEALTH PROTECTION BRANCH

- Laboratory Centre for Disease Control (LCDC)
  - Division of HIV/AIDS Epidemiology
  - Bureau of HIV/AIDS Laboratories and Research
- Drugs Directorate
  - Bureau of Biologics
  - Bureau of Human Prescription Drugs
  - Bureau of Drug Research

MEDICAL SERVICES BRANCH

- First Nations and Inuit Health Programs Directorate

MEDICAL RESEARCH COUNCIL OF CANADA (MRC)

CORRECTIONAL SERVICE OF CANADA (CSC)

* The National AIDS Secretariat originally reported to the Associate Deputy Minister of Health and Welfare, but has been a part of the Health Programs and Promotion Branch since June 1994.

In addition to the foregoing participants, the Health Canada International Affairs Directorate (IAD), whose mandate is to initiate, coordinate and monitor Departmental policies, strategies and activities in the international field, assists in the Strategy. During the first half of NAS II, IAD assumed responsibility for international liaison and coordination with other governments, agencies within and outside the United Nations system, and international NGOs - and gradually increased its collaboration with the National AIDS Secretariat. For example, IAD played a major role in the establishment of UNAIDS, in the planning and organizing of the Paris Summit on AIDS, and in the development of an International AIDS Strategy for Canada. Its continuing role is to ensure that Canada's position on AIDS issues at the international level are appropriately reflected and integrated into the overall Canadian positions at international health meetings.

A.1.2. PURPOSE OF THE MID-TERM REVIEW

The intent of the Mid-term Review is to assess if NAS II is on target, how well it is doing, whether the targets have changed, and if there is anything else that it should be doing. It represents a stock taking of whether all the essential ingredients and processes are in place, rather than an assessment of achievements and success to this point. The focus of the Mid-term Review is on the federal government components of the Strategy, and its orientation is primarily "top-down" instead of on the individual components.

More specifically, the Terms of Reference state that the Mid-term Review is to:

a) examine the extent to which structures, mechanisms, and processes that are critical for the success of NAS II have been established and are being maintained and used effectively;

b) assess the extent to which information and statistics that will be necessary to evaluate the National AIDS Strategy are available, or are being collected and will be available for the evaluation. This will include an assessment of the quality, dissemination, usefulness and use of the information; and

c) develop a panel study of non-government stakeholders to obtain information on the responsiveness of NAS II for both the Mid-term Review, and for use as a benchmark in the final evaluation to examine changes over time.

A.2. APPROACH AND METHODOLOGY

Three separate studies were carried out as part of the Mid-term Review. An **internal study**, focusing primary on Health Canada, reviewed program files and documents; consulted with selected federal officials in Ottawa, AIDS program officers in Health Canada's regional offices, and provincial epidemiologist and AIDS coordinators; and examined statistical and program information used to manage the Strategy. The "internal" study was carried out under a contract by the firm T.K. Gussman and Associates. The methodology employed and the interview guides used are described in Appendix A.

A parallel study conducted within Correctional Service Canada (CSC) involved document review and consultations with key officials in that organization. The **CSC parallel study** was undertaken internally by the Accountability and Performance Measurement Sector of Correctional Service Canada. Findings from the CSC parallel study have been summarized and incorporated in this report. The Table of Contents of the CSC report is shown as Appendix B.

The third element consisted of a telephone survey, carried out under a contract by Brighton Research, to obtain the views and perceptions of a cross-section of non-government stakeholders. This survey will serve as the first wave of a longitudinal **panel study**. The same individuals who were interviewed for the Mid-term Review will be asked the same questions again at the time of the final evaluation to assess the responsiveness of the Strategy and what changes have taken place over time. The methodology employed and a description of the panel are described in Appendix C.

Each of the three studies that were part of the Mid-term Review focused on four common issues - coordination, implementation, balance and information - that will affect the ultimate success of the Strategy. For example, because the Strategy involves partnerships with both government and non-government organizations at many levels, success will depend on how effectively government components, as well as non-government stakeholders, worked together, and how effectively their joint efforts were coordinated.

Similarly, the degree to which goals are successfully attained will depend on whether the Strategy was implemented as planned - whether it did what it said it would do. The issue of balance examines whether activities (such as education and prevention, development of models for care, treatment and support, and research) are being carried out in appropriate proportions.

Information is vitally important in identifying priorities and planning, targeting and implementing the Strategy. It will also be needed to evaluate the performance and success of NAS II.

The Mid-term Review looked at the availability, quality, dissemination, usefulness and use of information to manage and guide the Strategy, to ensure that the final evaluation will be able to assess how well and effectively NAS II achieved its objectives.

The remainder of this document on the Mid-term Review synthesizes the findings from the reports that were produced by the three sub-studies. The next four sections present findings on: coordination; implementation; balance; and information. The report concludes with a summary of main findings.

B. COORDINATION OF NAS II

B.1. GENERAL

The National AIDS Strategy works through networks of collaborative relationships with an array of partners. Effective coordination is vital, at many levels. It is needed among the federal components, between the Strategy and other federal departments, between individual components and other levels of government, between government and non-government organizations, and between Canada and other nations. The Mid-term Review looked at coordination from several perspectives: internally within the Strategy; between the Strategy and other federal agencies; between the Strategy and non-government partners and clients; and inter-governmental (i.e. federal/provincial/territorial) and international coordination.

Within Health Canada, a two-pronged approach was used to examine how well activities are coordinated. One avenue entailed reviewing files on the organizational structures and mechanisms used to exchange information and to discuss plans, priorities and activities. This line of enquiry was supplemented by discussions with program managers and officials about the effectiveness of those organizational mechanisms with which they were familiar. They were also asked about other formal and informal methods they employ to keep in touch with other components of the Strategy, their clients and partners in non-governmental organizations, and their counterparts in provincial governments. In addition, input about coordination of the National AIDS Strategy was obtained from provincial officials through both telephone discussions, and face-to-face meetings where possible.

The Correctional Service Canada parallel study focused mainly on internal coordination within CSC. However, it also addressed links with the wider community of health care providers, researchers and local HIV/AIDS organizations that provide post-release and support services needed by HIV+ inmates.

The panel study obtained input from a cross-section of non-government stakeholders in national and community-based NGOs, researchers, experts, professional care-givers, and persons living with HIV/AIDS. The panel, by design, included a subsample of individuals who were experts on HIV/AIDS in the "corrections" community or who were affiliated with organizations that serve HIV+ inmates, as well as a number of "on-reserve" Aboriginal respondents. The panel provides an external perspective on the coordination of NAS II, including coordination among non-government organizations.

This section describes the mechanisms and structures designed to achieve coordination and collaboration, and presents findings on the extent to which these are fulfilling their purposes.

B.2. OVERALL COORDINATION

Overall responsibility to coordinate NAS II and to monitor and oversee its implementation rests with the National HIV/AIDS Secretariat. It is responsible for facilitating the planning of the National AIDS Strategy, Phase II, and ensuring that all policies and programs are consistent with the Strategy's major goals. Although the Secretariat does not have financial authority over the components within the Strategy, it maintains a process for financial accountability including quarterly status reporting, periodic review of annual budgets and expenditures, and coordinating adjustments across the Strategy.

One of the Secretariat's key roles is to develop and maintain an effective network of working relationships among all elements of the Strategy. This includes within Health Canada; within the federal government (e.g. Justice, Customs, Citizenship and Immigration, International Development Research Council and the Solicitor General); with non-government partners; with the provinces; and in the international arena. A number of committees are pivotal mechanisms for the Secretariat's coordination role.

B.2.1. INTERGOVERNMENTAL COORDINATION

Two high level advisory committees have been established to provide advice to policy-makers on AIDS-related issues. They are the National Advisory Committee on HIV/AIDS (known as NAC-AIDS) and the Federal/Provincial/Territorial Advisory Committee on HIV/AIDS (referred to as the FPT). The National AIDS Secretariat is the official liaison for, and provider of secretariat services to both committees.

NAC-AIDS was established to advise the Minister of Health, the lead federal Minister on HIV/AIDS. Members are appointed by the Minister based on their knowledge in relevant areas. They represents diverse interests, regions, backgrounds (gender, Aboriginal, HIV positive, etc.) and a broad range of expertise, including the health, social, economic, legal and human rights fields. Their role is to bring policy issues to the attention of the Conference of Deputy Ministers (federal and provincial) through the Deputy Minister of Health Canada. This committee's mandate includes tracking emerging issues and trends; providing timely advice to the federal government, via the Minister of Health, on all aspects of HIV/AIDS; and providing a national forum in which to promote, enhance, and encourage collaborative initiatives and partnerships among federal and provincial governments and private sector stakeholders involved in HIV and AIDS in Canada. NAC-AIDS is required to meet four times annually for two days.

The **Federal/Provincial/Territorial Advisory Committee on HIV/AIDS** (FPT) is required to have one senior policy representative at the ADM level or equivalent from each participating jurisdiction. As of January, 1995 the FPT's mandate is to provide policy advice to the Conference of Deputy Ministers of Health, through the federal Deputy Minister, and to maintain appropriate linkages with the Advisory Committees on Population Health, Health Services and Health Information, as required. The committee brings together senior federal and provincial representatives knowledgeable in HIV/AIDS to assess issues, prepare options, provide briefings, and make recommendations to their health ministers. The FPT is required to meet twice yearly and to maintain frequent contact between meetings. One of the scheduled meetings includes a joint session with NAC-AIDS.

Both of these high level committees function as coordinating mechanisms that allow information sharing and discussion around national issues that contribute toward consensus building. Although federal and provincial officials did not comment about NAC-AIDS during interviews, the file review confirmed the value of this body.

Comments about the FPT were generally favourable. There is broad agreement that it focuses efforts of governments to collaborate and cooperate in areas such as information collection, policy development and program activities.

Although the need for the federal government to maintain a delicate balance between providing leadership and acknowledging provincial jurisdictions and political realities was noted by several provincial officials, there is general agreement that a more concerted effort must be made to bolster collaboration between levels of government. This is reflected in the common view that more frequent meetings and input from program staff are needed, even though conference calls have been held regularly since the beginning of 1994. The need for closer collaboration is seen as particularly important for planning beyond the end of Phase II of the Strategy in March 1998.

B.2.2. INTERDEPARTMENTAL COORDINATION

The Interdepartmental Committee on Human Rights and AIDS (ICHRA) led by Justice Canada is a formal mechanism for inter-departmental coordination. No comments regarding the operations of this mechanism were forthcoming during interview with officials. Further, the review of files revealed little evidence about this committee's activities. It is concluded that few officials have contact with this committee, and that its operation has little impact on the overall functioning of the National AIDS Strategy.

The Medical Research Council and the Correctional Service of Canada are components of NAS II that are not part of Health Canada. However, because they are participants in NAS II, coordination with these two organizations will be discussed later in the section on Internal Coordination.

B.2.3. INTERNATIONAL COORDINATION

Canada has various linkages with the international community regarding HIV/AIDS. Canada sits on the United Nations Programme Coordinating Board on which member nations discuss world health issues. LCDC works closely with the World Health Organization (WHO) to provide medical, epidemiological and laboratory expertise to assist developing countries in research. It also acts as a WHO Collaborating Centre for AIDS Research on AIDS. CIDA, the Canadian International Development Agency, provides funding for various initiatives in response to needs expressed by governments, UN organizations and Canadian organizations working in international development. The International Development Research Centre (IDRC) has funded approximately 37 HIV/AIDS projects in 13 developing countries as of 1995.

Aside from government agencies, various NGOs such as the Canadian Public Health Association (CPHA), OXFAM-Canada, CUSO, World Vision, and CARE Canada support international programs, and provide political support when called upon.

Headquarters respondents who commented on the coordination of international activities all indicated the absence of a focused approach. Current linkages, although considered vitally important, were described as having been forged in reaction to demands placed at the time. There was agreement that Canada lacks an international "Strategy" with respect to HIV/AIDS. Respondents questioned what Canada's role is internationally with respect to curbing the epidemic, and pointed to a need for more centralized and formal departmental coordination with respect to international organizations.

The National AIDS Secretariat is supposed to be the coordinating body, but there is some confusion around roles and responsibilities of the Secretariat, CIDA, and the International Affairs Directorate, which as noted earlier, was active in international liaison and coordination during the first half of NAS II. CIDA views itself as the lead regarding Canada's international Strategy, which blurs roles between agencies. Respondents described coordination between these organizations as *ad hoc*. Little evidence was found in the files (beyond World Health Organization and Pan-American Health Organization minutes at LCDC) regarding international coordination that takes place as part of NAS II.

Although the National AIDS Strategy has been criticized for lacking focus in international coordination, measures have been taken in this area. In response to these concerns and Canada's commitment to the Paris Summit of 1994, the AIDS Secretariat convened a group of individuals who were involved with the Summit to develop a framework document to initiate discussion for the preparation of an international Strategy. The working group made three recommendations:

a) there must be greater coordination among all Canadian agencies involved in HIV/AIDS;

b) there must be on-going involvement of Canadian positions and representation on international bodies, particularly those of the United Nations, to maintain a direct and influential role in stimulating and directing international responses to the AIDS pandemic; and,

c) there must be specific support directed at enhancing the capacity of Canadian agencies to intervene and advocate internationally for a more directed approach to dealing with the pandemic.

Some respondents were encouraged by the recent drafting of the discussion paper, Elaborating Canada's International HIV/AIDS Strategy, which raises important questions that require attention. It was reported that CIDA is under increasing pressure to cooperate with Health Canada, although results have yet to be observed.

With the notable exception of LCDC, which acts as a WHO collaborating centre for AIDS Research, there was little evidence of international coordination at the program level. Although individual program managers may attend conferences in their respective areas of activity, there was no evidence of any mechanisms in place to ensure that NAS II research, model building and resource development activities dovetail with, build upon, or complement activities in other nations.

B.2.4. NON-GOVERNMENTAL COORDINATION

The National AIDS Secretariat initiated a *National Partners Forum* in 1994, consisting of representatives from five major national non-governmental organizations involved in implementing the National AIDS Strategy in Canada. The members are the Canadian AIDS Society, the Canadian Association of HIV Research, the Canadian Foundation for AIDS Research, the Canadian Hemophilia Society, and the Canadian Public Health Association. The Forum, which is co-chaired on a rotating basis by the Secretariat and representatives from the NGO Partners, has met quarterly to promote, enhance and encourage collaboration between the Strategy and non-governmental organizations representing stakeholders from all provinces and territories.

The National Partners' Forum has served as a vehicle for disseminating information about trends in HIV/AIDS in Canada, for coordinating planning and preparations for major conferences such as the Paris Summit on AIDS and the XIth International Conference on AIDS (1996) in Vancouver, and for discussing issues such as research and the dissemination of findings. Although the Strategy is under no obligation to follow the opinions and advice of the Forum, the National Partners' input has been considered by the Secretariat's in its planning processes, and at the time of the Mid-term Review, efforts were underway to arrange for the Partners to have an opportunity to provide some input into the NAC-AIDS strategic plan.

B.3. INTERNAL COORDINATION

B.3.1. DEPARTMENTAL COMMITTEES

Several departmental committees have been established, and are the primary mechanisms for internal coordination. These include the AIDS Coordinators Committee, the Working Committee on Women and AIDS (WCWA), the Departmental AIDS Research Committee (DARC); and the Departmental Aboriginal AIDS Committee (DAAC). All Committees are chaired by the Secretariat, however DAAC was initially chaired by a representative of the Medical Services Branch (MSB).

The **AIDS Coordinators Committee** consists of representatives from each of the federal components. It was established as part of NAS II through the Cabinet Document process to serve as a vehicle for information exchange, identification of potential problem issues, coordination of HIV/AIDS initiatives, and problem solving. Initially, this committee met biweekly; in March 1995 it changed to a three week interval, adding one half hour to the length of meetings.

The **Working Committee on Women and AIDS (WCWA)** consists of representatives from all program units within Health Canada, the Women's Health Bureau and the Family Violence Prevention Unit. Its mandate is to ensure that Health Canada has a coordinated, effective approach to women's programming on HIV/AIDS. Its responsibilities include: developing a planning/conceptual framework for departmental initiatives; identifying emerging issues; contributing to policy development; monitoring departmental progress; and playing a general role in women's health issues with a particular focus on HIV/AIDS. Meetings were to take place monthly.

The **Departmental AIDS Research Committee (DARC)** consists of representatives from all program units in research directorates at Health Canada. DARC is intended to serve as a departmental forum to:

- share information on biomedical/clinical, public health service, epidemiological, and social and economic research projects on HIV/AIDS under development and being implemented;
- identify emerging research questions relevant to NAS II and suggest means of addressing such questions;
- provide input to the National AIDS Secretariat regarding coordination of a process to develop a national HIV/AIDS research plan for Canada;
- identify mechanisms for coordinating and promoting collaborative research among established groups; and
- promote, enhance and ensure coordination and collaboration among program officers involved in funding HIV/AIDS research projects.

DARC meetings are scheduled monthly or as needed.

The **Departmental Aboriginal AIDS Committee (DAAC)** is responsible for ensuring Health Canada has a coordinated and balanced approach to Aboriginal programming on HIV/AIDS. The committee was created to provide a forum for discussion of AIDS and HIV-related issues in the Aboriginal context. The files were not clear regarding who is required or invited to attend. DAAC was first chaired by representatives from MSB; it is now chaired by the Secretariat.

DAAC's specific responsibilities (based on a May 20, 1993 document) are to:

- promote and facilitate the exchange of information on proposed and current HIV/AIDS initiatives involving Aboriginal people;
- develop a planning/conceptual framework for departmental support of Aboriginal HIV/AIDS initiatives;

- provide a forum for identifying and discussing areas of special consideration; and
- monitor overall Departmental progress on Aboriginal issues.

The Committee met intermittently during the period reviewed.

B.3.2 MEETING ATTENDANCE

Review of administrative records provided one line of evidence about coordination. For example, analysis of the participation at the AIDS Coordinators meetings during the period from August 1993 to April 1995 showed two patterns of interest. First, Secretariat staff make up the majority of attendees. They represented more than 50 percent of those in attendance for 40 percent of meetings, approximately 45 percent 30 percent of the time, and about 35 percent the remaining 30 percent of the time.

Second, there is variation in how frequently various components participated at those meetings. Table 2 (see next page) shows the average attendance by component for the period August 1993 to April 1995, during which approximately 30 meetings were held. It indicates regular attendance by representatives of components within HPPB, but a lower attendance rate by those from HPB and MSB. There was no record of attendance by the Medical Research Council representative.

TABLE 2
ATTENDANCE - AIDS COORDINATOR MEETINGS

COMPONENT	% Attended
ACTSU	97%
AEPU	90%
ACAP	70%
LCDC	67%
NHRDP	63%
MSB	43%
Health Canada Rep. at CSC	30%
Drugs Directorate	23%
Medical Research Council	0%

(SOURCE: T.K. Gussman Associates Inc. Draft Report, Health Canada Internal Study)

Although one of the principal roles of the AIDS Coordinators meetings is to coordinate Departmental activities, evidence indicates that it is primarily a forum for information exchange. In interviews, AIDS coordinators acknowledged the value of that activity, but many expressed growing discouragement that the meetings do not discuss or address significant or emerging issues in a proactive way. In their view, although such a forum is an ideal way for participants to share ideas and plan future activities and enhance collaboration, the Secretariat is risking losing credibility in its ability to bring participants together toward a common purpose.

Analysis of the minutes of AIDS Coordinator meetings indicates that information tends to flow primarily from the Secretariat to those representing various components. Little two-way discussion was noted regarding issues of coordination and collaboration. From the majority of minutes examined, many representatives, particularly those from the Health Protection Branch, do not actively participate in meetings. With respect to strategic planning, there was evidence from recent meetings to suggest attempts are being made to discuss such issues as research planning, and ways to plan the National AIDS Strategy beyond Phase II.

Headquarters respondents indicated that the other departmental committees meet less frequently, and tend to be reactive to emergent issues. The file review confirmed this in part. It indicated that the Departmental AIDS Research Committee meets monthly on a consistent basis, and that attendance at meetings is usually 75 percent. However, the Women and AIDS Committee, and the Aboriginal AIDS Committee have not met regularly. Files indicate that meetings are supposed to be scheduled monthly or whenever required, however, both committees have met at most once or twice per year. The Aboriginal AIDS Committee last met in February 1995 where it was decided that the committee will plan an Aboriginal issues agenda and attempt to determine which components of the Strategy have responsibility for research and other activities.

Some respondents said that the time required to attend committee meetings combined with regular AIDS Coordinator meetings and staff meetings is excessive. In many cases, the same individuals are asked to participate on multiple committees. File review evidence confirmed that the same individuals who attend AIDS Coordinator meetings also attend various committee meetings. As well, it was found that agenda items are often duplicated between these fora. One official pointed to repetition in discussions between committee meetings, which takes time away from other matters.

B.3.3. CORRECTIONAL SERVICE CANADA

The main link between Correctional Service Canada and the Strategy is through the CSC National AIDS Coordinator (a Health Canada employee seconded to the Health Services Sector Corporate Advisor) who is a member of the NAS II AIDS Coordinators Committee, and liaises with other Health Canada committees, community based organizations, provincial AIDS coordinators, etc. There are other linkages associated with funding at the program level, and between evaluation staff at CSC and Health Canada on evaluation-related matters.

Health Canada respondents involved with CSC projects said it has been challenging to build a relationship with the Service, given differences in culture and administrative systems. However, they indicated that both Departments are learning from each other in terms of monitoring programs, coordinating efforts, and developing policy options. They said the most challenging aspect of this project is attempting to integrate the pilot projects CSC has undertaken as part of NAS II into regular Correctional Service programming.

The parallel study carried out by Correctional Service Canada reports that the CSC National AIDS Coordinator has an informal network that includes Health Care staff in prevention, education, research, care, treatment and support, and joint projects. These informal mechanisms are supplemented by a National Working Group tasked with the implementation of bleach kit distribution and anonymous HIV testing. There are no other coordination mechanisms or structures within the Service to ensure consistent implementation of the accepted recommendations of the Expert Committee on AIDS and Prisons (ECAP).

The CSC parallel study report notes that, unlike other CSC high profile initiatives, the AIDS dossier lacks the direction and coordination of someone sufficiently senior to ensure CSC actually carries out the mandate to which it has committed itself. No formal structures, implementation frameworks or data bases are in place to facilitate program delivery, monitor progress and assess impacts. Although the CSC National AIDS Coordinator is responsible for pursuing the implementation of ECAP recommendations, the Coordinator has no functional authority over regional and/or Health Services staff. The CSC report notes that coordination of HIV/AIDS activities has been impacted by the implementation of a five-year Long Term Organizational Plan to eliminate, streamline or re-engineer the work of the CSC headquarters and regional headquarters. It observes on the need for various responsibility centres within CSC to become more involved, and for a broad integrated response to HIV/AIDS.

B.3.4. MEDICAL RESEARCH COUNCIL OF CANADA

Apart from its participation with NHRDP in their joint HIV/AIDS research and career development funding program, the Mid-term Review found no evidence of collaboration with MRC in the National AIDS Strategy Phase II.

During discussions regarding the Terms of Reference for the Mid-term Review, it was learned that the Council's activities, including those supporting AIDS/HIV research, are guided by its mandate and internal review procedures. Regardless, it was suggested that there might be value in the Strategy undertaking a major review of research activities on a global scale to identify where to concentrate Canadian research so it could make the greatest contribution. Such a review would also serve not only to ensure that Canada was not supporting research activities that were duplicating work done elsewhere, but it would identify knowledge already available that was relevant and useful in Canada.

B.3.5. PROGRAM AND MANAGEMENT COMMITTEES

Departmental committees are supplemented by a variety of other internal committees in which the Secretariat does not play a role. Among these are the Drugs Directorate Expert Advisory Committee (EAC) on HIV Therapies, and several program committees in individual responsibility centres.

Drugs Directorate EAC members are selected on the basis of medical expertise, basic and applied science expertise, knowledge of community needs and expertise in ethics. The committee's mandate is to provide medical, scientific and clinical advice on current and emerging issues that relate to the work of the Drugs Directorate, and HIV therapies and vaccines, specific HIV/AIDS related products, and HIV/AIDS research developments in Canada and internationally. It was formed as a forum for advice and a sounding board for management and scientists of the Drugs Directorate. However, other sections of Health Canada may consult it to seek advice or information on work related to HIV infections, therapies or research. In addition, the *Departmental Working Group on HIV Therapies* is closely associated with the Drugs Directorate EAC. The EAC is to schedule two meetings each year, and more if required by the Directorate.

A number of program areas hold annual or semi-annual meetings in order to focus activities. For example, ACAP staff meet twice annually to discuss program issues and invite representatives from other components to speak about issues that may have an impact. The Division of HIV/AIDS Epidemiology convenes an annual meeting with provincial epidemiologists and lab directors to discuss surveillance and data issues, and the Division's annual work plans and priorities.

Other programs such as AEPU, ACTSU, and First Nations and Inuit Health Programs (MSB), organize regular staff meetings where activities of other components may be discussed. In the case of ACTSU, there are numerous examples of staff updating other components through meetings and memoranda about their activities. In addition, ACAP and ACTSU publish and distribute reports describing their mandates and inventories of their on-going projects.

B.4. SUMMARY OF INPUT ON COORDINATION

Almost all federal respondents acknowledged that coordination among federal components needs improvement. However, the difficulties cannot be attributed solely to those coordination mechanisms that are in place. Attention must also be paid to political and economic realities, and to the need to overcome branch insularities. Components can better use the established mechanism to their full potential.

With some exceptions (notable, the on-going liaison between ACAP, ACTSU and AEPU), coordination among programs tends to be limited primarily to information sharing, with limited emphasis on overall strategic planning and resource allocation. The general consensus is that the components are not in tune with each other. Some programs make an attempt to inform others of their activities while others are less forthcoming.

Information from files and interviews indicates that some programs such as NHRDP, and the Bureaus of Biologics, Drug Research, and Human Prescription Drugs within the Health Protection Branch, tend to not actively coordinate their activities with other components, although there is evidence that representatives (except for the Bureau of Biologics) occasionally participate in AIDS Coordinator Meetings or share information. In most cases, this lack of coordination is attributable to the nature of the work.

Although opinion is split on the merits of building or expanding ad hoc bilateral relationships, some programs have followed this path to address the pressures of retrenchment and the lack of clarity in objectives. Such cooperation between programs has had various effects, not the least of which is improved collaboration in activities that overlap these programs. In the words of one official, the shift away from vertical coordination through such bodies as the National AIDS Secretariat toward more bilateral arrangements between program units is a fact.

File information indicates a growing emphasis on forms of ad hoc bilateral arrangements from 1992 to present. There are many examples of correspondence between individual program units, annual meetings, and conference calls where representatives from other components have been asked to participate. This may indicate natural progression to a more program-focused approach, but it may also compromise accountability in the absence of careful monitoring.

Overall, coordination of federal components needs improvement. Both the mechanisms in place and the manner in which they are utilized require improvement. Almost all respondents agreed that the role of the committees should be revisited, regardless of whether they felt that the committees were yielding benefits. For the most part, coordination at present is restricted to information sharing, with little emphasis on overall strategic planning in resource allocation or long-term programming.

Need for improvement in the coordination between components was noted too. There is general consensus that components are not in tune with each other. For example, some headquarters respondents in the Health Protection Branch saw little if any coordination between the units in the Branch, let alone with components in other branches. Some respondents want stronger linkages between the "science" of HIV/AIDS and the "programs" designed to address the epidemic.

Although coordination at the regional level is variable, in most regions there is little active collaboration between federal program areas, other than requests for specific information. Moreover, some regional respondents noted that at times provincial officials knew about headquarters initiatives before regional officials did. Regional respondents reported mounting pressures to improve communication and coordination.

A main concern raised by almost all federal and provincial officials was the lack of indication about "who is in charge of the Strategy". There is a perception that no agency or group of people is guiding the Strategy. One provincial official stated that "...the Strategy is behaving like a band without a band-leader". However, other respondents were positive, observing that because the work of the Strategy is carried out with little intervention from senior managers that the "AIDS file" operates as if it were an integrated Departmental program.

A number of federal respondents indicated there was lack of clarity regarding the overall direction of the National AIDS Strategy. Both headquarters and regional program officials were familiar with the Strategy's stated objectives, but they were generally unclear about how these fit together. It was commented that "there is no glue that binds the components together or serves to ensure they are working toward a common vision".

Many suggested that the National AIDS Secretariat has not provided sufficient leadership. Respondents who are not in the Health Programs and Promotion Branch indicated that responsibilities to their own ADMs usually take precedence over the Secretariat's requests. It is noted that the Secretariat has been impacted by several changes in its reporting relationships during the past year and a half. Further, there has been high turnover of Secretariat staff, with the attendant frequent need to devote effort and energy to familiarization with program's responsibilities and activities.

Almost all respondents said that an effective central coordinating agency should have available the tools to allow it to maintain a balance between components. In other words, the coordinating body should have some influence over budgetary decisions and have the ability to reallocate funds where appropriate.

In this regard, it must be informed regularly of monetary demands on components and have the authority to reallocate funds from programs with under-utilized budgets.

Equally important, the coordinating body should have some responsibility for policy development and decision-making, in concert with senior management and stakeholders. Policy development allows for clear and timely debate on issues of importance. Accordingly, components would know and understand that there is a forum for discussion of the issues, and a process for making policy decisions.

Some respondents said that currently there is no forum for "making course corrections" or for "making policy decisions which apply to all components equally". That is, there is no organization, at present, which has responsibility for "seeing the macro picture". A few respondents wanted to see a body within the Strategy which has the legitimacy and ability "to push the agenda" to ensure that activities and responsibilities are carried out. They saw such a group as ensuring that Strategic activities are "cutting edge" and "demonstrate leadership".

In this regard, responsibilities to maintain accountability are vitally important, and respondents were not confident that the National AIDS Secretariat does or can perform these activities. They said the Secretariat has too low a profile both within and outside the Department to influence components or effect change. Some officials stated that an approach that relies almost completely on the goodwill of components to cooperate "...was doomed to fail from the beginning".

Some respondents suggested that the lessons learned from the experience of the implementation and dismantling of the provincial AIDS Secretariat in British Columbia might be relevant to the National AIDS Secretariat. These are:

- a clear mandate and objectives have to be established for the coordinating agency;
- the agency must have the ability to make budget decisions which affect all aspects of the Strategy;

- clear processes around funding administration, and stakeholder and government representation around important decisions have to be agreed upon in advance of implementation;
- the agency must have responsibility for policy development;
- the agency must have principal responsibility for coordination, and the accountability to ensure that components are performing appropriately; and,
- the political will and commitment from senior management is critical to the success of operations.

B.5. STAKEHOLDER PANEL

The stakeholder panel provided some information that is relevant to coordination. Panel members were asked to rate NAS II overall on its coordination using a 5-point scale, where "1" means "not at all adequate" and "5" means "very adequate". The results are presented in Table 3 (see next page).

There was an almost even balance between panellists who rated overall coordination less than adequate and those who rated it better than adequate. About one quarter of the panel members rated the coordination neutrally (a "3" on the five-point scale). However, a relatively high proportion (about one fifth) did not know or had no answer. The issue of coordination appears less relevant to panellists associated with organizations that focus on specific populations such as inmates and First Nations communities.

Perhaps the main aspect of concern to panellists is to have NAS II provide more resources and direction relating to coordination. This could range from the simple collection and dissemination of information to organizations with similar mandates through to electronic networking and more opportunities for face-to-face meetings. The need for coordination activities appears to be varied, and based on the needs of various regions and sub-populations.

Although about one fifth of the stakeholders did not comment on coordination, almost all of them did comment of their ability to provide input to the NAS II agenda and priorities. Table 4 (see next page) presents stakeholders' views on this issue.

TABLE 3
PERCEIVED ADEQUACY OF NAS II'S OVERALL COORDINATION

	Organizational Affiliation of Panellists						
Ratings on NAS II "Coord."	**Total**	**Comm. Based**	**Hospital**	**Assoc.**	**Univ./ Found**	**Aborig.**	**Corr.**
1 and 2	34	14	4	4	7	4	1
3	29	9	4	6	6	2	2
4 and 5	28	14	5	4	2	3	0
NA/DK	24	5	2	2	6	4	5
Number of Panellists	N=115	N=42	N=15	N=16	N=21	N=13	N=8

(SOURCE: Brighton Research, Panel Study of Stakeholders, Research Report)

TABLE 4
PERCEIVED ABILITY TO PROVIDE INPUT TO NAS II AGENDA AND PRIORITIES

	Organizational Affiliation of Panellists						
Perceived ability	**Total**	**Comm. Based**	**Hospital**	**Assoc.**	**Univ./ Found**	**Aborig.**	**Corr.**
1 and 2	63	26	7	8	7	10	5
3	14	4	2	2	2	2	2
4 and 5	33	12	5	5	10	1	0
NA/DK	5	0	1	1	2	0	1
Number of Panellists	N=115	N=42	N=15	N=16	N=21	N=13	N=8

(SOURCE: Brighton Research, Panel Study of Stakeholders, Research Report)

In general, stakeholders' perceptions about their ability to influence the Strategy were critical. More than half of them say they have little or no ability to provide input on setting and adjusting NAS II's agenda and priorities (about twice the number who say they can provide a great deal of input). This view predominates among panel members affiliated with community-based organizations, in the corrections-related field and in Aboriginal on-reserve organizations.

It is recognized that there is substantial "organizational distance" between most stakeholders and the coordinating bodies at the core, such as the national committees, the AIDS Coordinators, and the National AIDS Secretariat. Certain national non-governmental organizations which are partners in NAS II function as principal "spokepersons" for the broader community of HIV/AIDS interests. For programs serving community-based clients and service providers, direct contact is normally through staff at the regional and field level. Indeed, while some stakeholders felt a need to be able to provide input to the Strategy, others indicated that it was the role of the national NGO partner to act as their conduit. Nonetheless, the weight of stakeholders' views on this issue signals a need to review more closely how well the established coordination and communication channels are working.

A number of the perceptions of external stakeholders that are consistent with those of and government officials merit particular mention. Many panel members identified the need for the Strategy to coordinate more with other national and provincial organizations as the single most important change to improve NAS II. A perception of lack of leadership was cited by some non-government stakeholders in the panel study. The National AIDS Secretariat was singled out by some as needing more authority, presence and direction. These commonalities reinforce the need for attention to these issues.

C. IMPLEMENTATION

The issue of implementation looks at whether NAS II has done what it said it would do. This includes examining if things were not done that should have been done, and if there were things that were done that stray from what had been envisioned. How well NAS II has been implemented was examined two ways - through the internal reviews, and from the perspectives of non-government stakeholders. The CSC parallel study, in particular, focused extensively on this aspect of NAS II within that organization.

Limitations were encountered with both approaches. Federal respondents reported that departmental monitoring and tracking information was unreliable, and that other mechanisms such as progress reports do not provide an honest picture. Evidence was drawn mainly from interviews with federal officials at headquarters and in the regions, although some information obtained from file reviews was analyzed. Many non-government stakeholders felt they did not know enough about the National AIDS Strategy as a whole to provide overall ratings on the implementation of NAS II, although most were able to provide feedback on more specific areas. The findings from each perspective will be presented in turn.

C.1. HEALTH CANADA INTERNAL REVIEW

Federal respondents interviewed as part of the Health Canada internal review provided little feedback on the overall implementation of NAS II. That the majority did not comment on this aspect at all might be interpreted as a general absence of criticism. However, in view of the limitations in available reporting and monitoring information that were noted above, such a conclusion would be tenuous.

It is generally believed that positive strides are being made against the epidemic. While many respondents believe the Strategy is working, this view is guided by their perceptions of their own contribution. Although internal progress reports relay information on the status of specific initiatives implemented by individual components, there does not appear to be any means of consolidating responses to determine overall whether efforts under the Strategy are unfolding as had been planned. Factors such as frequent Departmental reorganizations and lack of adequate central coordination and information (i.e. centralized data), confound an accurate accounting of the Strategy's implementation.

Ten percent of the federal respondents commented on NAS II expenditures, which relate to implementation of the Strategy. They suggested a need for a review of administrative requirements to optimize the use of resources. In their view, unused (internal) operations resources should be transferred to services and programs if the amounts and sources of unused funds could be identified early enough in the fiscal year. We note that this was also suggested by some of the non-government stakeholders.

Review of file documents identified some interesting patterns in the variance between plans and actual implementation. An analysis of unspent funds in the first two years of NAS II showed that, even after adjustments for re-profiling and reallocations, there had been unspent funds in both years for coordination and collaboration, education in MSB, and Blood Safety in HPB. In both years, the largest lapse was for coordination and collaboration.

The National AIDS Secretariat, which is responsible for overall coordination of NAS II, lapsed one sixth of its budget in the first year, and one quarter of its budget the second year. This was attributed mainly to the fact that the Secretariat is operating at 75 percent of its allocated staff complement, which may impact on its ability to perform its coordinating role.

A comprehensive and detailed examination of the annual program plans and corresponding annual reports for each of the components to assess the implementation of the Strategy would have been desirable. Unfortunately, it was not possible to obtain annual plans, priorities and progress reports for all components within the time constraints of the study. Information that was available for two components indicates that they prepared annual plans and priorities in collaboration with their clients, and there was a measure of flexibility in the implementation of their program activities.

It is not possible to draw general conclusions regarding the implementation of mechanisms and processes for planning, priority setting and monitoring of the implementation of the Strategy. However, comments presented in the section on Information suggest that although mechanisms to manage and monitor programs and projects are under development, further improvement is still needed.

C.2. CORRECTIONAL SERVICE CANADA

The National AIDS Strategy of the Correctional Service of Canada involves three program elements: Policy Development; Program Delivery and Evaluation; and Issue Management. CSC developed a multi-year action plan that delineated the actions to address each accepted ECAP recommendation and identified specific time frames and responsibility centres. The CSC parallel study compared the action plan to the status of implementation at the time of the Mid-term Review.

In Policy Development, work to revise existing policy and develop new policy on HIV/AIDS, particularly those affecting delivery of health care services, is on-going, but the new Commissioner's Directive on management of inmates with HIV has yet to be finalized.

In the area of Program Delivery, a number of educational materials for inmates were produced and distributed; self-teaching materials such as *practice guidelines* were provided to clinical staff; and a joint health education project in B.C. Region provided AIDS information sessions for all inmates and staff of all federal and provincial institutions. A number of initiatives to promote links with community groups were completed or are on-going. Four pilot projects/ initiatives were undertaken in response to the ECAP recommendations. These were:

- a pilot project on bleach kit distribution in Pacific Region;
- a national implementation framework for bleach kit distribution;
- a national implementation framework on anonymous HIV testing;
- a pilot project on use of a paid inmate peer health promotion worker.

The first of these projects has been completed, the remainder are on-going. In addition, the Service is conducting research on injection drug use and other high-risk behaviours, and an inmate survey.

In Issue Management, the Service has developed and maintained expert knowledge and analysis of AIDS issues in federal prisons as they emerge; developed and maintained partnerships and networks in the AIDS and public health fields; and provided input to communications plans or materials developed for the media on AIDS in CSC facilities.

The CSC parallel study found that while some progress has been made in some areas, the National AIDS Program is behind schedule in relation to the work plan developed in fiscal year 1994-95. The delays encountered so far can be attributed to the lack of many of the fundamental elements identified in the earlier section that examined coordination within CSC (see page 19). Lack of an implementation framework, program delivery mechanisms, accountability framework, etc. have a major impact on CSC's ability to assess priorities, the best response to these priorities, and its ability to design and deliver the necessary programs. The CSC parallel study report emphasizes the need to take an integrated approach to planning and implementation of activities related to HIV/AIDS.

C.3. STAKEHOLDER PERCEPTIONS

Members of the stakeholder panel had mixed perceptions on how well NAS II had been implemented overall. The distribution of ratings is shown in Table 5.

TABLE 5

RATINGS OF NAS II ON ITS IMPLEMENTATION

	Organizational Affiliation of Panellists						
Ratings on NAS II "Implement."	**Total**	**Comm. Based**	**Hospital**	**Assoc.**	**Univ./ Found**	**Aborig.**	**Corr.**
1 and 2	29	15	2	1	6	2	3
3	30	9	6	8	3	1	3
4 and 5	28	12	4	3	6	3	0
NA/DK	28	6	3	4	6	7	2
Number of Panellists	N=115	N=42	N=15	N=16	N=21	N=13	N=8

(SOURCE: Brighton Research, Panel Study of Stakeholders, Research Report)

About one quarter of the panellists declined to provide a rating. The remainder were almost evenly spit between those who were critical (gave ratings of 1 or 2 where 1 means "not at all adequate"), those who were neutral, and those who judged the implementation as adequate or very adequate (gave ratings of 4 or 5 where 5 means "very adequate"). Most of the critical ratings were found among stakeholders affiliated with community-based organizations, universities/foundations/research centres, and in the corrections-related field.

Some of the critical ratings may be related to how funding has been distributed to date. Panellists' feedback about this is shown in Table 6 (see next page). Although one quarter of the stakeholders felt unable to rate NAS II on the adequacy of its distribution of funding, of the 85 who provided feedback, almost 45 percent were critical, whereas less than 25 percent rated NAS favourably. Critical ratings were especially predominant among stakeholders affiliated with community-based organizations, universities/foundations/research centres, and in Aboriginal on-reserve organizations.

However, the ratings shown in Table 6 (see next page) must be interpreted with care. When participants were invited to comment on how NAS II had affected their ability to conduct activities and provide services, of 27 comments provided that specifically mentioned funding, **only three** were negative. Moreover, fully 80 percent of the non-government stakeholders indicated that implementation of NAS II had helped them conduct a desired range of activities. This suggests that what the negative ratings on the distribution of funding in Table 6 mean, is that even though implementation of NAS II has been helpful to stakeholders, there is room for improvement. The stakeholders' feedback on "balance" presented later in this report addresses where improvements may be made.

TABLE 6
STAKEHOLDER PERCEPTIONS OF ADEQUACY OF NAS II'S DISTRIBUTION OF FUNDING

	Organizational Affiliation of Panellists						
Ratings on NAS II "Dist. of funding"	**Total**	**Comm. Based**	**Hospital**	**Assoc.**	**Univ./ Found**	**Aborig.**	**Corr.**
1 and 2	38	18	2	2	10	4	2
3	27	10	6	3	3	3	2
4 and 5	20	6	4	6	3	1	0
NA/DK	30	8	3	5	5	5	4
Number of Panellists	N=115	N=42	N=15	N=16	N=21	N=13	N=8

(SOURCE: Brighton Research, Panel Study of Stakeholders, Research Report)

D. BALANCE

The issue of balance is related to and reflects on what has been done, and provides a second way of examining the implementation of NAS II. It asks whether there is need for adjustments in the relative emphasis among the various activities that comprise the Strategy. For example, if certain areas have been consistently unable to use the level of funding available to them, it would indicate that an in-depth critical review is needed.

However, the patterns of variance between plans and expenditures discussed previously are only one indicator. Even if all areas had been consistently able to use all the resources available to them, program managers, specialists and provincial officials may have insights on which areas are more wanting, and whether there are areas in which efficiencies are possible or better focusing is desirable.

A critically important perspective on balance is provided by external partners, stakeholders and clients, who are closer to the outputs of the Strategy than are those responsible for delivering them. The assessment of this issue considers information from all of these sources.

D.1. HEALTH CANADA INTERNAL STUDY

Government officials were asked whether NAS II "is doing the right things" and the extent to which activities are "balanced" in a way that maximizes benefit. Respondents who indicated there was room for improvement were asked to suggest how they would realign resources. In addition, they were asked to determine what level of government, if any, should be responsible for providing services or performing the tasks indicated and how roles and responsibilities ought to be divided among jurisdictions.

Approximately three quarters of federal respondents and two-thirds of provincial respondents offered an opinion regarding balance. Those not responding said that they lacked either the information or global perspective necessary to formulate an informed opinion. Evidence used to assess balance was derived primarily from interviews, although some file evidence was used regarding the financial aspects of the Strategy.

Overall, there was consensus among federal and provincial officials that the Strategy is working, attributed largely to the commitment and personal relationships that have been built. Some stated that inadequate central coordination has compelled individuals to coordinate their efforts despite the differences in goals and objectives of the various components. Most agreed that a more effective coordinating mechanism would create greater efficiencies.

Almost all federal respondents saw the major activities associated with the National AIDS Strategy as necessary and appropriate. In many regions, federal involvement is believed to be "the only game in town". Consequently, there is high dependence on federal presence through the AIDS Strategy to provide necessary programs and services.

In jurisdictions with high provincial involvement, both federal and provincial respondents see the participation of the federal government as very important. Federal government participation implicitly lends credibility to provincial initiatives. As one official explained, "...the federal government can get away with much more than provincial governments. It can draw attention to an issue like AIDS because it can highlight it as a national problem that has to be addressed".

Although all respondents agreed that the federal government has a role in AIDS programming and services, they said that some reassessment is necessary. Given that almost all provinces and territories are now delivering services, the federal government should focus its efforts on key areas that yield the most benefit.

Over half the federal and provincial officials consulted believe that NAS II's current "blanket" approach may not be appropriate any longer. The federal government must focus its activities where it can do the most good, and reduce resources for activities where provincial governments could be more active. It was indicated that any federal government decision to decrease involvement should be preceded by a review of the degree of provincial readiness or ability to take over current federal initiatives.

Overall, these respondents said that a balancing of activities is needed within the Strategy. More importantly, they believe that the federal government must tailor its activities by region to ensure comparable levels of HIV/AIDS service across the country. Resources would have to be allocated in collaboration with provincial or regional efforts.

Specifically, initiatives such as federally funded education and prevention programs have yielded benefits, but the view is that provincial governments should be "picking up" such responsibilities. Respondents would redefine the federal role in this area to target national awareness campaigning about the potential effects of HIV/AIDS.

The majority of respondents said that more federal resources are needed in the areas of developing care and clinical treatment therapies, enhancing awareness about HIV/AIDS among high risk groups such as prison populations and youth, and developing training guidelines and curriculum for professional caregivers.

Whereas most officials believe that community development activities are still necessary, there was division as to which level(s) of government ought to have responsibility for this activity, which includes operational funding. Some respondents believe that the federal government has generated a community response in many jurisdictions to address the effects of HIV/AIDS. They suggest it is now the responsibility of provincial and local governments to ensure that such efforts continue. On the other hand, some respondents wanted the federal government to be a strong and active participant to ensure all regions have equal and comparable access to local services.

Approximately one quarter of all respondents indicated that more linkages with community groups are needed to ensure that they have the tools necessary to meet their "front-line objectives". Devolution of responsibility from the federal and provincial governments to local or community groups was seen as vitally important as the need for care and treatment grows. Despite the divergent views regarding what level of government ought to be responsible, almost all agreed that local governments and community groups must be the focal point for HIV/AIDS initiatives. The role of both the federal and provincial governments is to ensure that local and community groups are properly equipped to perform their responsibilities.

Overall, all respondents indicated that the optimal role for the federal government is to provide a national focus by coordinating research, policy, information and training. Provincial officials in particular viewed the federal government as the most capable of pulling provincial strategies together and ensuring national consistency in data gathering and research activities. Accordingly, they said the federal government could provide a national context for provincial programs in terms of research and epidemiological surveillance. Table 7 presents a summary of the alignment of responsibilities that was suggested by most federal and provincial respondents.

TABLE 7
SUGGESTED ALIGNMENT OF FEDERAL/PROVINCIAL/TERRITORIAL RESPONSIBILITIES

FEDERAL	PROVINCIAL/TERRITORIAL
Education and Prevention	**Education and Prevention**
* national awareness * maintain National Clearinghouse (research etc.) * national curriculum for prevention training * supplement project specific funding	* regional or group specific social marketing * implement culturally appropriate education and prevention activities * operational funding for community groups
Research	**Research**
* applied research (i.e. "big ticket" projects) * national epidemiological surveillance * independent drug testing and regulation	* collection of regional epidemiological data * application of national research into programs * HIV/AIDS testing and analysis
Care, Treatment, Support	**Care, Treatment, Support**
* implement a national training institute for CHRs and other community workers * develop curriculum for treatment workers and trainers (set national guidelines) * assist in development of treatment programs	* develop and implement clinical care, treatment, and support programs * principal funder of programs * development of regional policy on programs
Community Development	**Community Development**
* national liaison with national stakeholders * national information dissemination	* principal funder (core funding) and link with provincial and regional stakeholders
Coordination & Collaboration	**Coordination & Collaboration**
* liaison with federal components * development of national policy * linkage with international community	* link with provincial/regional networks

(SOURCE: T.K. Gussman Associates Inc. Draft Report, Health Canada Internal Study)

D.1.1. GAPS IN NAS II PROGRAMS AND ACTIVITIES

Respondents were asked whether they were aware of any areas of deficiency in the Strategy. Several areas were frequently mentioned. These are discussed below.

a. AIDS programs and surveillance in First Nations communities

Almost all federal and provincial respondents in all components noted an insufficiency of AIDS programming for Aboriginal communities. MSB officials in both headquarters and the regions said that it is the Department's intention to devolve on-reserve programs within a time frame to be determined in consultation with First Nations and Inuit. They view devolution as a positive and achievable goal. However, overall the Department has not provided adequate training for First Nation communities regarding how to assume responsibility for health services, including how best to deal with HIV/AIDS.

MSB officials believe the federal government has a responsibility to ensure that First Nations are equipped to provide services in the area of HIV/AIDS in a manner that is timely and appropriate for the community involved. Specifically, adequate and appropriate training should be designed to ensure that necessary skills have been transferred to provide a level of service comparable to non-native communities.

About half of the respondents commented about the variable division of roles between the federal and provincial levels of government regarding First Nations HIV/AIDS programming. Both federal and provincial respondents were uncertain about their respective responsibilities. In some jurisdictions, federal and provincial officials have built a relationship such that roles are intentionally blurred, allowing for greater cooperation and coordination of resources, particularly with respect to off-reserve programming.

AIDS surveillance was cited as a major source of concern. In many jurisdictions the quality of on and off-reserve data is questionable. Moreover, First Nations people are highly mobile, further complicating data collection and tracking because they may move from the reserve for periods of time, or may live off the reserve.

Many HIV+ individuals from First Nations ultimately return to their communities at advanced stages of the disease. Home care resources in communities that need them are viewed as inadequate. More holistic and culturally-appropriate approaches are needed to address challenges associated with HIV/AIDS because approaches taken from non-native communities have been found ineffective.

Creating awareness about the effects of HIV/AIDS on-reserve was another area noted as inadequate. Officials reported little marketing (i.e. attention and effort) directed toward building understanding of AIDS, condom use, needle exchange, or sexual activity. One official expressed the view, echoed by other respondents, that "building awareness in native communities is at the level the rest of the population was at in Phase I". In addition to building awareness, approximately one-third of respondents said that attention must be paid to studying risk behaviours (peer based) in both native and non-native communities.

b. Linkage between scientific research and policy and program development

Many senior headquarters program managers and both federal and provincial epidemiologists and researchers observed that the link in the Strategy between pure scientific and applied research, and policy and program development appears to be tenuous. For example, NHRDP/MRC peer review committees do not include members from other components or backgrounds who would ensure that consideration is given to the potential application of research to policy development or program enhancement. Likewise, aside from frequent updates of epidemiological surveillance from LCDC, scientific researchers or epidemiologists are often under-represented in discussions leading to program or policy development. These respondents would welcome stronger bridges between sciences and programs.

c. Financial resources and training for community-based organizations

Most respondents observed that inadequate federal resources appear to flow to community-based organizations relative to other strategic activities. ACAP respondents in particular noted that the program budget has been insufficient to meet the needs of community groups. Though there is division as to what level of government is responsible for community-based funding, there was agreement among most respondents that the principal objective of the ACAP program is to provide community groups with the resources needed to build a capacity to deliver HIV/AIDS programs where gaps existed. The federal government has initiated a process at the community level to deliver needed services. Many respondents question who will be responsible for operational funding or community-based funding generally after Phase II of the Strategy concludes. But regardless of responsibility, there is still a demand for community-based training for caregivers and other professionals, and for expanding the capacity of many community organizations to address a rising demand for services.

D.1.2 REVIEW OF RESOURCE ALLOCATION

About two-thirds of all respondents believe there ought to be a review of financial resource allocation in the National AIDS Strategy. (The remainder stated that they lacked a global view to make an informed contribution.) Overall, they said that all major activities in the Strategy are necessary and appropriate. However, most federal regional and provincial respondents believe that some activities clearly require greater attention.

Approximately one-half of those who believe there should be a review of financial resource allocation (i.e. one third of all officials consulted) suggested how they would re-allocate funds. Table 8 (see next page), which is presented in the form of a balance sheet, provides a summary of the comments, organized in terms of the major NAS II activities. The left column, labelled "less support", indicates where respondents thought funding should be reviewed and re-allocated to cover those aspects in the right column, labelled " more support".

TABLE 8
SUMMARY OF COMMENTS REGARDING RE-ALLOCATION OF FEDERAL SUPPORT

ACTIVITY	LESS SUPPORT	MORE SUPPORT
Education and Prevention	* prevention programming	* education programming particularly among youth and Aboriginal peoples
Research	* AIDS surveillance * Basic science research * Clinical Trials Network	* HIV database * research in risk behaviours and HIV tracking (applied) * research into drug therapies
Care, Treatment, Support	* AIDS Information Service * Community training of caregivers and other professionals	* Treatment therapies * National training standards and curriculum development
Community Development	* divergent views	* divergent views
Coordination and Collaboration	* Administrative support for AIDS Secretariat	* Policy advisors to enhance coordination

(SOURCE: T.K. Gussman Associates Inc. Draft Report, Health Canada Internal Study)

It should be noted that Table 8 provides a general summary about re-allocation. Although the information is presented by activity, each column should be regarded as an envelope. That is, the appearance of items on the same line should not imply that funds should be transferred from one item to the other. Respondents generally indicated that funds should be reviewed and/or reallocated from the "less support" to one or more functions on the "more support" side. The table is intended to show those functions which are perceived to be in need of greater or less attention.

In the "research" activity, the shift of emphasis from AIDS surveillance to an HIV database requires elaboration. AIDS represents a medically defined state of progression of the disease that may take ten or more years to develop after the HIV virus is contracted. At that point, the disease is "reportable", which means that a physician is required by law to report it. Federal epidemiological data report on AIDS. By way of contrast, HIV is the presence of the disease virus, even though it might be in a relatively latent or asymptomatic state for many years. HIV is not reportable in most jurisdictions, although certain provinces are compiling and reporting HIV statistics.

D.2. CORRECTIONAL SERVICE CANADA

The CSC committed itself to a range of activities in eduction and prevention, care, support, and research. These activities involve different target groups among both inmates (general, women and Aboriginals) and staff (security, health care, other). They also involve different programs, and different stages of the custody continuum from induction to after-care.

While CSC has made a commitment to a balanced response through accepting the majority of the ECAP recommendations, achieving balance means that the Service will implement the accepted recommendations. The slow progress to date, and the obstacles discussed earlier in this report in the sections on Coordination (see p. 19) and Implementation (see p. 31), will make it difficult to achieve a balanced response to the ECAP recommendations before the National AIDS Strategy sunsets in March 1998. There is still a lot of ground to cover if CSC is to address the differing needs of different target groups within the Service.

The CSC parallel study observed that implementation is closely related to coordination, and until program design issues are addressed, implementation will remain difficult and the Service will fail to achieve a balanced response. Coordination, implementation and balance are inter-related, and they all rest on having a program design model that will facilitate an integrated CSC response to the ECAP recommendations.

D.3. STAKEHOLDER PANEL

Stakeholders were asked for their perception of whether the current balance among the activities in the Strategy (for example between education, care, research, etc.) is appropriate. Many panellists (43 of 115) did not provide input on this issue. However, only 22 percent of the panel members felt the balance of NAS II was appropriate, while 41 percent, almost twice as many, felt the balance was not appropriate. The responses are shown in Table 9.

TABLE 9
PERCEPTIONS OF APPROPRIATE BALANCE IN NAS II Strategy

	Organizational Affiliation of Panellists						
Appropriate Balance	**Total**	**Comm. Based**	**Hospital**	**Assoc.**	**Univ./ Found**	**Aborig.**	**Corr.**
Yes	25	9	5	1	4	5	1
No	47	19	6	8	12	1	1
DK NA	43	14	4	7	5	7	6
Number of panellists	N=115	N=42	N=15	N=16	N=21	N=13	N=8

(SOURCE: Brighton Research, Panel Study of Stakeholders, Research Report)

Those who said that current balance was inappropriate were asked their reasons. Most of the panellists' supplementary comments focused on the need for and role of research. Of the 23 stakeholder comments on this activity, 18 indicated there was need for more emphasis on research, although perhaps with a different focus.

The second most frequently cited activity was education and prevention. Of the 12 stakeholder comments, all but one indicated a need for more emphasis on this activity. The remaining stakeholder suggested there should be less education and prevention because it does not appear to be working.

Eight panellists felt there was need for more care and support. One suggested that it should be recognized that AIDS is a long-term chronic disease like cancer, and there is need for greater emphasis on integrated sustainable care.

Panellists were asked to identify from where they thought resources might be obtained in order to attain better balance. Of 27 comments provided, one third (9 panellists) suggested redistributing funding from research. Eight panellists suggested that funding be obtained from other non-AIDS program areas, and several suggested resources could be obtained through more efficient government operations. No consensus or predominant patterns were discerned.

To further explore what adjustments might be appropriate, stakeholders' perceptions on the performance of NAS II were analyzed, even though that information was collected primarily to allow longitudinal comparative analyses in the final evaluation. Panellists' views on what they regraded as the most successful and the weakest aspects of the Strategy reveal a variety of sometimes contradictory perceptions, with a near equal balance between positive and negative comments.

Of the 88 comments regarding the **most successful** aspects, most centred on the funding support provided (17), the level of awareness achieved (16), the development and availability of resource materials (15), the community-based emphasis (14) and the overall coordination provided (13).

Of the 99 comments identifying the **weakest** aspects of NAS II, the most prevalent areas cited were funding (21), administration (20), lack of communication (18) and lack of strategic leadership (12). While 13 viewed the overall coordination provided as the most successful aspect of NAS II, there were 9 respondents who identified lack of coordination as the weakest aspect.

The lack of consensus among stakeholders is illustrated by the fact that the numbers of stakeholders who cited research as the most successful aspect of NAS II was equalled by the number who regarded research as the Strategy's weakest aspect. Although there is considerable divergence in the feedback obtained, the clustering of critical responses focusing on the lack of coordination, communication, strategic leadership and administration, which accounts for 59 of the 99 negative comments, warrants mention.

D.3.1. SINGLE MOST IMPORTANT CHANGE TO IMPROVE NAS II

Stakeholders were asked to identify what they thought was the single most important change to improve NAS. There were 35 comments relating to funding, but they were quite varied. They included 5 mentions of the need for more funding, 6 mentions for more stable funding at appropriate levels, and 5 mentions for increasing funding for community-based care. Others identified a need for more efficient funding, a change in emphasis based on a review and evaluation of funding and its impact, more equitable funding, and eliminating waste.

Other areas of improvement frequently mentioned included the need for more input from more stakeholders (19 mentions). There was a strong theme revolving around more local input and tailoring to regional, rural and local issues. There is a generalized felt need for more openness in decision making and for far more people in various organizations to feel they are part of the Strategy.

The need for a more segmented approach and focus to improve NAS II received 19 mentions too, but they were quite diverse. Some felt the Strategy should direct greater attention to the needs of rural, remote areas and certain population groups. Others suggested the need for more emphasis on research on gene therapy, more emphasis on male to male transmission of the disease, more focus on getting provincial governments to act, and more public education.

There were 12 calls for more research in general, which came from panellists in all groups except those affiliated with professional associations, but the views diverged in terms of the areas in which more research was needed. One panellist suggested reduced levels of pure research, and increased effort devoted to therapies.

There were 10 comments about the need for commitment by the federal government to the Strategy. Four panellists said the greatest need was for internal leadership, eight suggested that the single biggest thing to improve the Strategy would be to begin detailed planning now for Phase III. Four panellists, all affiliated with hospitals, indicated need for the Strategy to coordinate more with other national organizations and the encouragement of other coordinated efforts with the provinces. The National AIDS Secretariat was singled out as needing more authority, presence and direction.

E. INFORMATION

One of the Mid-term Review's main objectives was to assess the extent to which the information and statistics necessary to evaluate the success and effectiveness of the Strategy are available or are being collected. This required examining what information the National AIDS Secretariat and components are compiling on: what they have done; what tangible outputs they have generated; and what difference NAS II has made on the epidemic. Of particular importance in this regard are epidemiological statistics to monitor how the epidemic is evolving and whether there have been changes in the epidemic in response to the Strategy's activities. More specifically, the review examined the availability, quality, dissemination, usefulness and use of information.

Both the internal reviews and the stakeholder panel included questions about information. The internal reviews examined what information was available, and obtained the views of officials about its quality, usefulness, and actual use. A major emphasis in the internal reviews was on information and epidemiological statistics to manage the Strategy and components' activities. In contrast, stakeholders' assessments usually referred to information they received as clients of NAS II, which in many cases are outputs of the Strategy.

E.1. HEALTH CANADA INTERNAL REVIEW

In examining this issue, this report will distinguish between management information and epidemiological statistics, and examine them separately. It also comments on research reports funded under NAS II.

Management information deals with what was done, how much, when, where, by whom, and why. It is **internal** information that describes the inputs, activities and outputs that are controlled by program managers. It is information that is usually recorded as part of normal program administrative.

Another type of management information records what happened or, especially in the case of funding programs, what was produced as a direct consequence of a program's activities. This may be information that is **external** to the program, and therefore it must be actively collected.

Epidemiological statistics describe disease conditions in the population. They can be used in a proactive manner to identify target populations for program activities, and to identify priorities for action by identifying the severity, distribution and patterns in the disease (i.e. who is ill, how many there are, where they are, what the trends are).

These statistics can also be used retrospectively, to assess the broader impacts and effects of programs by monitoring changes in the trends in the disease and patterns among sub-populations and regions. This information, in turn, allows determining in successive planning activities whether changes are indicated in the type or level of program efforts, or the targeting of efforts.

Research reports present information about the results of scientific enquiries. Studies related to HIV/AIDS may include biomedical, pharmaceutical and nutritional research, as well behavioural research and studies of models for delivery of care and services.

E.1.1. MANAGEMENT INFORMATION AND MONITORING MECHANISMS

Federal government respondents were asked about the appropriateness and adequacy of monitoring structures and mechanisms. This has two facets. Do components have the tools necessary to adequately monitor their activities and determine whether their initiatives are having an impact? In addition, are there adequate means to determine whether the Strategy overall is being monitored in a useful and appropriate way?

Most programs use a combination of Departmental monitoring mechanisms such as the Departmental Financial System (DFS or CATIE) and internally-developed tracking processes. Respondents reported that Departmental systems such as the DFS are unreliable because information is frequently faulty and not timely. Other mechanisms utilized by the Strategy such as progress reports do not provide "an honest picture" about the impacts of the NAS II. One official regarded the Strategy's monitoring as principally "show and tell".

About one-third of federal respondents lack confidence in the Department's financial and project management systems. Many view the information generated by these systems as inadequate for their purposes and presented in a format difficult to understand. Consequently, many components have implemented alternative tracking systems that provide information more relevant to their particular needs. While there are obvious benefits to tailor-made information systems, these independent systems defeat the rationale of a centralized system, which is to reduce potential duplication and generate standardized reports.

Almost all headquarters respondents believe that sound project monitoring is vitally important as a resource during revisions of project funding for renewal purposes. However, many consider that project/financial tracking systems developed internally by programs are still in their infancy. The components developing systems are still in the process of "working out the bugs" to make certain they yield accurate results and are an effective use of resource time.

Almost all federal respondents indicated that components do not do a good job monitoring impacts. Some indicated that self-evaluations by stakeholders have yielded mixed benefits. Although several components are in the process of developing and/or implementing more reliable means of tracking the financial aspects of projects and initiatives, there remain few ways of determining whether federal activities are having an impact.

Respondents believe current monitoring activities do not provide a global picture of the Strategy's activities. As noted earlier, many respondents believe the Strategy is working based on their components' perceptions of their own contribution, and on internal progress reports that relay information on the status of specific initiatives implemented by individual components. However, there does not appear to be any means of consolidating information at the Strategy level to determine, overall, whether efforts are unfolding as had been planned.

Almost half of the federal regional respondents have responsibility for administration of more than one Health Canada program. Consequently, time to perform all expected responsibilities is limited. Although they regard monitoring as useful, it is frequently an activity that diminishes in priority relative to other pressing assignments and responsibilities. One official noted that "in order to get through the day, one learns quickly what is important at the time... other things must wait. Unfortunately, monitoring is one of those activities".

Approximately one-third of federal regional respondents commented that the federal government places much emphasis on ensuring that funding proposals are well-scrutinized. However, less attention is paid to how funds are utilized by recipients or whether they have yielded intended impacts.

Some respondents stated that funding recipients place little importance on monitoring their activities. Often no one is designated to track expenses or performance. Therefore, federal officials find it difficult to determine and quantify impacts. However, most said they were able to assess impacts qualitatively through regular contact with recipients. They acknowledge that qualitative impacts are difficult to assess and represent accurately through formal mechanisms. A joint approach to monitoring was suggested as a possible alternative. Questionnaires or detailed self-evaluation forms were suggested as potential tools to assist recipients.

The review found that it is not possible at an overall level to determine whether NAS II is doing what it set out to do, and that impacts will be difficult to measure. However, some components are making efforts to develop evaluation models and indicators. Some officials underscored a need to develop more quantitative measures such as outcome indicators or proxy measures, to more accurately determine impacts. It is anticipated that such efforts will be reflected in the National AIDS Strategy final evaluation scheduled for the fall of 1997.

E.1.2. EPIDEMIOLOGICAL SURVEILLANCE DATA

Federal officials and provincial epidemiologists and laboratory directors were asked to comment on the relevance, usefulness, and appropriateness of AIDS statistical reports from various sources.

Almost all respondents indicated that the quality of AIDS data in Canada is high. In their view, LCDC's National AIDS Case Reporting Surveillance System (ACRSS) yields reliable, standardized data. A few epidemiologists observed that sometimes there are discrepancies between the provincial data submissions and final results. In addition, they questioned the representativeness of the AIDS population data.

Almost all epidemiologists agreed the AIDS data tend to be conservative. However, in their view, that is more desirable than data based almost exclusively on modelling, which may or may not be realistic.

There was division of opinion regarding the degree of under-reporting or conservativeness. Some argued under-reporting is as low as 10 percent, while others said it was as high as 30 percent. Overall, these respondents said the data currently are accurate within acceptable confidence parameters, and provide a useful idea about trends and the general state of the epidemic. Respondents at LCDC explained that there are frequently differences in data submitted from the provinces and final results due to "data cleaning" and "rounding".

Provincial epidemiologists indicated that their AIDS data from 1986/87 onward are approximately 85 percent reliable when compared with current reporting systems. With respect to HIV data, some provinces (where HIV is reportable) said their data are 60 to 75 percent reliable from 1989/90 to 1993/94. HIV data during that period are mainly historical and are acknowledged to be incomplete. These respondents believe that after 1994, reliability improved to between 95 and 100 percent due to more advanced reporting systems.

Respondents identified a variety of factors which limit the reliability of data, particularly about HIV. The most notable factor is that high risk groups tend to be highly mobile and may ask to be tested frequently in various jurisdictions. Efforts to improve data reliability are complicated by anonymity and confidentiality provisions which make it difficult to detect duplicates in reporting. Efforts are underway to find unobtrusive ways to identify test recipients without openly identifying individuals. Respondents said this is "a tricky question that requires innovative solutions".

Another factor affecting the reliability of HIV data is under-reporting in some jurisdictions. Respondents repeatedly called for standardized approaches to data collection protocols to ensure a reasonable degree of confidence in national data. Some jurisdictions are currently searching for ways to improve data protocols.

A significant factor which limits the reliability of HIV data is the variation in regulatory provisions among the provinces. Specifically, HIV information is not "reportable" in all provinces, although it is collected. In jurisdictions where HIV is not reportable, respondents were not sure about the extent of under-reporting except to say it is substantial because reporting is voluntary. In addition, in some jurisdictions such as Quebec, privacy laws regarding information make it difficult to report data in a way that does not cross legal boundaries. It was agreed that much negotiation is needed to overcome these complicating factors, but it would be worth the effort.

One quarter of federal and provincial respondents that deal with LCDC offered an opinion regarding its activities. This group comprises epidemiologists, provincial officials, and federal respondents in various components outside LCDC. The remaining respondents were either not asked about their relationship with LCDC or indicated they were not informed enough to comment.

All these respondents indicated that the design and implementation of a national HIV database is taking too long to bring to fruition. Some suggested that incentives to provinces, such as federal financial or technical field support, would significantly quicken the pace of design and implementation.

Almost all who responded thought that benefits would flow from greater LCDC leadership in designing relevant data systems and facilitating collection from provincial counterparts. This would require bringing together all relevant epidemiological centres, laboratories, and anonymous testing centres to make decisions regarding the most useful information to collect and how best to share it. Consultations via conference calls and annual meetings are seen as useful, but it is often difficult to secure a commitment to proceed around key issues. It was suggested by epidemiologists in particular, that LCDC lead by example and provide incentives to provinces to cooperate.

With respect to federal data collection activities, most respondents who offered comments expressed the desire for LCDC to focus its efforts on designing and implementing databases and reports that provide "a state of the nation picture".

Although LCDC's openness in providing advice and services was applauded, there is a desire for the federal centre to provide a national voice for epidemiological activities which can not easily be provided by provincial centres.

All respondents were asked to comment on the usefulness of statistical and surveillance information produced and disseminated by federal sources. Views varied among federal and provincial respondents.

Almost all headquarters and regional federal respondents said that various statistical sources such as LCDC reports were useful, to the extent that they demonstrate whether the epidemic is being affected. When probed about whether this information is considered in the design or amending of programs, about half indicated affirmatively, but they could not explain precise linkages. The other half either said that such reports were not vital for this purpose, or that programs were designed to be "cutting edge" or are supposed to be ahead of the data. Statistical information was thought to provide limited insights.

Provincial respondents (other than epidemiologists) were asked how they used federal statistical information, specifically AIDS surveillance reports. Almost two-thirds said they found the reports useful, to the extent that they provide national scope. To determine the status of the epidemic on a provincial basis, these respondents rely primarily on provincial sources. The remaining provincial respondents were unable to offer an opinion.

Overall, respondents said that although AIDS information is useful in terms of highlighting the epidemic from a national perspective, more information about HIV would be welcomed. All respondents believe LCDC information to be valuable in the sense that AIDS surveillance is required, but greater attention must be paid to gathering HIV/AIDS intelligence on high risk populations and risk behaviours.

About one-third of respondents noted that media articles about HIV/AIDS are frequently inaccurate. This is of interest in light of the fact that epidemiological statistics are made public regularly.

Several reasons were offered to explain this. First, reporters may not have backgrounds in statistics, and may unknowingly sacrifice precision and accuracy in their effort to report key findings in a concise manner. For example, a reporter may be told that the median age of infection for HIV in 1990 was 23 years. If the reporter thinks "median" is synonymous with "average", interprets "age of infection" to mean how old the person currently is, and does not distinguish between AIDS and HIV, they might report "*Average AIDS Victim is 23*".

Second, reporters may not appreciate the difference between an estimate and actual documented cases, or the media may knowingly use estimates to write a more interesting story because estimates tend to be generally higher or less conservative than documented figures.

Third, the statistics presented may not be properly understood. For example, if a reporter is not aware that statistics described as "cases reported" represent cumulative counts, the numbers may be interpreted as **new** cases in a reporting period. It is noted that the LCDC Quarterly surveillance update: AIDS IN CANADA uses the former unit of reporting, whereas the British Columbia AIDS UPDATE Quarterly Report presents statistics in terms of annual cases.

Finally, several respondents reported that they had been misquoted by the media, and have had to follow-up on inaccurate reporting. Some have made a decision not to talk to the media without prepared written notes which can be explained to reporters.

Almost all respondents agreed that information has to be presented to the media in a clear and concise manner to reduce the incidence of inaccurate reporting. Statistics must be provided in a format that is easily understood. Finally, some respondents suggested that the language of HIV/AIDS must be standardized in some way to reduce confusion about definitions and the meanings of terms.

E.1.3. RESEARCH REPORTS

Respondents were asked to comment generally on the relevance and usefulness of research produced and disseminated by federal sources. Federal and provincial respondents were uncertain about what research is being produced or how research priorities are determined.

Federal respondents were asked about the usefulness of research reports emanating from NHRDP and/or MRC. More than three quarters said that although they are not direct users of this form of information, they pass on to provincial agencies and other stakeholders "anything interesting that crosses their desk".

The remaining quarter of this group work primarily in the sciences. These respondents said they have an interest in the work of NHRDP and MRC, but do not actively or routinely seek out research reports. They occasionally receive reports from the Secretariat, but few could explain how useful such reports were, other than to say that they appeared to be informative.

With regard to provincial respondents, including provincial epidemiologists, few had a clear sense about the research activities of the National Health Research Development Program or the Medical Research Council. Although there is some knowledge about the guidelines to submit proposals to NHRDP, few could clearly identify the research priorities or types of initiatives undertaken. More importantly, these respondents repeatedly inquired about how NHRDP establishes its research priorities and how such priorities contribute to collective knowledge about the epidemic. From their point of view, there is no indication as to whether research is being used in a way that justifies expenditures.

The small minority of federal or provincial respondents who were aware of some NHRDP/MRC research activities questioned the timeliness of the research. They contended that the window for relevant and timely research for HIV/AIDS is very short. This group of respondents generally indicated that more applied research is needed regarding risk behaviours in high risk populations such as intravenous drug users, street youth, homosexual men and off-reserve native people. Moreover, the research should be completed in a way that contributes to policy development so that programs can be designed which address specific needs. Again, respondents indicated that the bridge between policy development and research has to be improved to facilitate a greater exchange of information.

There is little knowledge about the work of the NHRDP and MRC, or the types and relevance of research being carried out or funded under NAS II. There is a need to synthesize research findings into policy development, and to guide program planning and design.

E.2. CORRECTIONAL SERVICE CANADA

The CSC parallel study examined the availability and quality of management information about several NAS II-related activities at Correctional Service Canada.

The CSC maintains a simple database on reported HIV/AIDS cases in CSC facilities. Reports are issued on a monthly basis by National Headquarters to help decision making on resource allocation and evaluation of the effectiveness of interventions. These statistics reflect only reported cases, which probably underestimate the actual number of cases. Outside observers such as ECAP have identified that ad-hoc information gathering exercises are needed to indicate the extent to which the number of reported cases is an accurate measure of the CSC situation. However, the clear trend of steady increases in the number of cases is accurate and alarming.

During the month of December 1995, 149 of approximately 13,000 federal inmates were known to be infected with HIV and an additional 16 had AIDS. This represents a substantial increase from the 56 of 12,838 federal inmates known to be infected as of January 1992, and suggests an overall infection rate in Canadian institutions of one in 88 inmates (1.14 percent). However there is evidence that the actual prevalence of HIV in federal institutions is higher.

The only seroprevalence study undertaken in a federal institution in Ontario (Joyceville) revealed an HIV-infection rate of one percent. Seroprevalence studies have several limitations, particularly in the prison environment. In particular, observed prevalence may be an underestimate because individuals who consider themselves at high risk of HIV infection may choose not to participate in a study. Nevertheless, these studies have consistently shown that rates of HIV infection in inmate populations are much higher than in the general population in Canada, and that the HIV infection is a serious problem in Canadian correctional institutions.

The CSC parallel study noted that operational experts confirm that CSC should explore alternative measures of the extent of HIV/AIDS within its institutions, such as addressing barriers to voluntary testing in order to make inmates more comfortable with the notion. Development of an anonymous testing program for national implementation is expected to increase the number of inmates coming forward for testing and eventual care, treatment and support similar to the experience in the outside community with voluntary testing. Implementation of this CSC program will lead to more accurate data on the extent of the disease and allow for some estimate of the extent of under reporting.

E.3. STAKEHOLDER PANEL

Panellists were asked about the availability, completeness, accuracy, timeliness and usefulness of information disseminated by NAS II in their own main field of activity. This includes reports and other descriptive material about NAS II and its components intended for public distribution and the Strategy's external clients, as well as resource materials prepared by the NAS II components. Some panellists' comments also apply to information resources prepared with NAS II funding, and information distributed by the CPHA Clearinghouse. Overall, their ratings were generally positive, but there was variation.

Panel members' feedback on information disseminated by NAS II is presented in Table 10 (see next page). They rated the availability of information from NAS II using a 5-point scale where "1" means "very poor" and "5" means "excellent". Slightly more panellists rate the availability of information positively (N=41) than negatively (N=37). This pattern holds true across organizational affiliations except for hospitals and associations. Those with hospital affiliations are much more negative (9 low ratings vs. only 3 high ratings) while those with associations are much more positive (only 1 low rating and 8 high ratings). The number of “Don’t knows”, at 19, is midway between the levels found for other questions.

TABLE 10
RATINGS OF AVAILABILITY OF INFORMATION FROM NAS II

	Organizational affiliation of Panellists						
Ratings of available NAS II "info."	**Total**	**Comm. Based**	**Hospital**	**Assoc.**	**Univ./ Found**	**Aborig.**	**Corr.**
1 and 2	37	15	9	1	6	4	2
3	18	10	0	3	3	1	1
4 and 5	41	15	3	8	6	6	3
NA/DK	19	2	3	4	6	2	2
Number of panellists	N=115	N=42	N=15	N=16	N=21	N=13	N=8

(SOURCE: Brighton Research, Panel Study of Stakeholders, Research Report)

Stakeholders rated information from NAS II highly on the key attributes of being useful and accurate. It is seen as being at least adequate in terms of perceived availability and completeness, and to a lesser extent timeliness. That roughly one fifth of panel members did not respond to these items (i.e. answered "don't know" or felt the question did not apply to them) is worth noting. So too is the fact that on the whole, about another third of the panel members gave low ratings to the quality of NAS II information.

Some panellists indicated a need for dissemination of information to the community level, (though others made favourable mention of the CPHA Clearinghouse). This suggests a lack of awareness of information services and resources available through non-governmental sources. A number commented that NAS II had a poor dissemination Strategy, and no effective mechanism to disseminate information. Others criticized NAS II for being too narrowly focused on certain groups and excluding others. Three panel members involved in community-based activities complained they received too much non-relevant information.

In addition to rating information from NAS II on the selected attributes, panellists were asked for their suggestions on how to improve the information from NAS II. Numerous suggestions were offered, covering a variety of areas that in some cases extend beyond the federal government role. However, a number that are relevant to federal NAS II components merit mention.

About one sixth of the comments (from all groups) indicated interest in more and/or more frequent information about NAS II activities and priorities. More than a tenth of the stakeholders identified a need for better data - on HIV surveillance, on various target populations and Aboriginal specific statistics. This included need for more information "tailored" to cultural/linguistic/ethnic groups and to rural issues. It was also suggested that a directory of research be issued regularly, along with research results where available.

F. SUMMARY OF MAIN FINDINGS

F.1. COORDINATION

The Mid-term Review examined coordination at both a Strategy-wide level, and at the level of components. This included reviewing what coordinating mechanisms or structures the National AIDS Strategy, Phase II (NAS II) had in place, and how well they were operating. Information from all three studies carried out as part of the Mid-term Review was used to corroborate findings.

At the Strategy-wide level, most of the necessary coordinating mechanisms are in place. The National Advisory Committee on AIDS and the Federal/Provincial/ Territorial Advisory Committee on HIV/AIDS represent vehicles for policy input and information sharing on national issues and priorities. The National AIDS Secretariat's liaison with the forum of "national partners" provides a linkage with the non-government sector. Although there has been uncertainty with regard to international coordination, steps have been initiated to clarify roles in this arena.

The high-level coordination mechanisms, with the possible exception of the international aspects, are functioning effectively. However, a need for more active or intensive collaboration has been signalled in connection with the need to chart a course for beyond NAS II. The HIV/AIDS epidemic will not disappear when Phase II of the National AIDS Strategy ends. Given the fiscal climate faced by all governments, and it will be necessary to review and decide what must be done and who is best positioned to do it. This may require additional effort to ensure that the necessary time and energy is directed and devoted to mid-range national planning.

Although steps have been taken to clarify roles for formal international coordination, there are broader needs at the more applied program levels. With some exceptions, there is limited international liaison by NAS II components. Mechanisms have not been established to routinely exchange information with other countries in areas such as research, development of educational and prevention resources, and evaluation of models of care.

While it is recognized that the characteristics of the epidemic differ widely in various societies, doubtlessly there are lessons to be learned from the experiences in other countries, and areas where Canada can contribute. This will require development of a Strategy for, and more centralized departmental coordination of informal international coordination on applied matters.

There are four departmental committees for Strategy-wide internal coordination on which the National AIDS Secretariat plays a key role. Two of these committees meet regularly, the other two only sporadically. Although the Departmental AIDS Coordinators Committee meets regularly, attendance across components is not uniform. Components that are not part of the Health Programs and Promotion Branch attend erratically. The Review found no evidence of attendance by the Medical Research Council representative.

Until recently, this committee has functioned primarily as a forum for information exchange. There was little proactive planning and discussion of how to manage emerging issues. Program coordinators indicated that the committee was not being used to full advantage. The focus of this committee appears to be shifting to place more emphasis on discussion of policy, emerging issues, and planning for beyond Phase II of the National AIDS Strategy.

The Departmental AIDS Research Committee, a forum to share information on the full spectrum of HIV/AIDS research activities and to identify relevant emerging research questions, meets regularly and its meetings are reasonably well attended. The other two departmental committees have not met regularly. Some agenda items of the committees are duplicated. In many cases the same individuals are asked to participate on several committees. On the whole, the departmental committees are not operating effectively as coordination mechanisms. Overall coordination of federal components of NAS II needs improvement.

There is also need for improvement of coordination among components. Although there is effective information sharing between some programs, others work in comparative isolation. The lack of linkages between most "science" components and program components was noted in particular.

The Correctional Service Canada parallel study reported that, other than the informal contacts of the National AIDS Coordinator and the creation of the National Working Group on implementation of bleach kit distribution and anonymous HIV testing, there are no other coordination mechanisms, structures or implementation frameworks within the Service that ensure consistent and uniform implementation of the accepted ECAP recommendations by the various sectors impacted by HIV/AIDS (e.g. Research, Legal, etc).

Coordination at the region level is variable. In some regions there are frequent meetings between federal program consultants, and regular interchange of information with provincial counterparts. The arrangements are more ad hoc and the contacts less formal and frequent in other regions.

There is fairly widespread concern about the National AIDS Secretariat's effectiveness and leadership in coordinating activities. This stems from changes in its reporting relationships (with an attendant diminishment of perceived "clout"), its lack of authority to actively manage NAS II resources, frequent staff turnover and, and failure to use departmental committees as collaboratively fora to work proactively on policy and planning issues with program coordinators. It is significant that many external stakeholders perceive leadership and coordination as areas in need of improvement.

In summary, the National AIDS Strategy involves coordination on many fronts. At the global level, most of the necessary mechanisms are in place, but some changes are needed. There is need to enhance internal coordination, both vertically and laterally to increase collaboration. At the working level, improvements can be made in some areas.

F.2. IMPLEMENTATION

On the whole, there is little criticism with the implementation of NAS II. Most program areas feel they have made positive strides in responding to the epidemic. Unfortunately, in most areas there is a dearth of readily accessible "hard" information to document exactly what has been done, and with what effect. There is little Strategy-wide descriptive information. Financial information reveals some shift and variances between what had been planned and what was actually done. Of particular interest, resources for coordination have lapsed, indicating that less was done than planned. This is noteworthy in view of the need for improved coordination that was identified above.

The scarcity of management information in most areas points to a significant deficiency with regard to the objective of monitoring the performance and effectiveness of NAS II. Although some components are developing information systems on the management and operation of their programs, progress is slow. There is a need to ensure it will be possible to "roll up" information to provide a Strategy-wide picture of what is being done, where, for whom, and to what end.

The Correctional Service Canada parallel study reported that while some progress had been made in some areas, the CSC National AIDS Program is behind schedule in relation to the workplan developed in 1994-95. A major organizational re-engineering and downsizing, which was implemented concurrently with the HIV/AIDS program under a five-year Long Term Organizational Plan, had a resulted in high staff turnover and significant structural changes at Headquarters.

Stakeholders are generally satisfied with implementation of NAS II. Eighty percent indicated that implementation of NAS II had helped them conduct a desired range of activities. They did, however, identify areas in which improvements in balance can be made.

F.3. BALANCE

Most government officials indicated that all the major activities of NAS II were necessary and appropriate. Apart from identifying a need for more effective coordination, most comments about balance were stated in terms of what activities should be carried out by the federal as opposed to provincial governments. The principal need for balance was not among activities per se, but for tailoring of activities by region, in light of what provincial services were available, to ensure comparable levels of HIV/AIDS services across the country.

Overall, respondents suggested that the federal government should be responsible for activities that require a national focus, and those that involve developing resources. These include coordinating research, policy, information and training. In that connection, it was suggested that more federal resources should be devoted to developing care and clinical treatment therapies, enhancing awareness among high-risk groups such as prison populations, and developing training guidelines and curricula for professional caregivers. Provincial officials view the federal government as most capable of developing a national context to provide coherence for provincial strategies and to ensure consistency in data gathering and research.

It was felt that although federal education and prevention programs have yielded benefits, provincial governments should be picking up such responsibilities. The development of community-based capabilities, which had been supported by the federal government, was identified as another area in which provinces could assume responsibility.

Input from officials identified a number of gaps, notably in services and culturally appropriate programs for First Nations communities, and a gulf between "science" and programs. This was corroborated by input from some members of the stakeholders' panel. The Correctional Service Canada (CSC) parallel study indicated that slow progress and obstacles in coordination and implementation will make it difficult for the Service to achieve a balanced response to the ECAP recommendations before the National AIDS Strategy sunsets in March 1998.

Many federal respondents suggested that resources within NAS II should be reallocated. The need to reduce support for AIDS surveillance, and to increase support for developing a national HIV data base and research into HIV tracking is particularly noteworthy. The need for statistics on HIV, which may take many years to develop into AIDS, and are more valuable to monitor trends and focus program efforts, is supported by provincial officials. The need for more resources for coordination was reiterated. This general area (coordination, communication, strategic leadership and administration) was identified by a majority of the stakeholders as the Strategy's weakest aspect.

F.4. INFORMATION

On the basis of the information reviewed in the Mid-term Review, it would be difficult at this time to evaluate the performance and success of NAS II. Current monitoring activities do not provide a global picture of the Strategy's activities. Departmental financial and project management information systems are not used by many components because the information provided by these systems is frequently faulty and not timely. Many components have opted to develop alternative tracking systems tailored to their needs, but these are still in their infancy and bugs are being worked out. It is not possible to consolidate information from these tailor-made systems to produce standard Strategy-wide reports.

It is accepted by program officials that the components do not do a good job monitoring impacts. Self evaluations by stakeholders and NAS II clients have yielded mixed benefits. Development of tools and skills to assist them are needed. At this time there are few ways of determining whether the efforts under the Strategy are unfolding as had been planned, or of determining whether federal activities are having an impact. However, some components are making efforts to develop evaluation indicators and information systems.

The epidemiological data collected by NAS II through the National AIDS Case Reporting Surveillance System is generally acknowledged by almost all respondents for being high quality, reliable and standardized. However, AIDS data, by its very definition reports on the disease only when it has progressed to a point that a number of symptoms are evident. HIV data, in comparison, are based on the initial evidence that the person has contracted HIV virus. Many years can pass before the disease progresses to the point that AIDS is diagnosed and reported. AIDS statistics have a retrospective character that diminishes their usefulness in monitoring the spread of HIV, and identifying risk factors and trends in a timely enough manner to guide programs.

There is broad consensus that more effort is needed to design and implement a national HIV data base. As a national agency, the Laboratory Centre for Disease Control (LCDC) is regarded as best situated to lead in this area.

There appears to be little use made of results of research funded by the National Health Research Development Program (NHRDP) or the Medical Research Council (MRC), and no input into the selection of research projects by "non-scientist" program mangers. A need for more attention to research into risk behaviours in high risk populations was identified.

Although CSC collects statistics on infectious diseases, the database is relatively simple and has few data elements. The parallel study noted the need to assess the database and explore the requirements for additional information.

APPENDIX A

METHODOLOGY AND INTERVIEW GUIDES - INTERNAL COMPONENTS

1. INTRODUCTION

The mid-term review of NAS II comprised separate internal and external components. The "internal" review focused on government officials and files. This section describes the issues addressed and the lines of inquiry used in the internal review.

The internal review had two objectives. The first was to examine the enabling conditions that are critical to the Initiative's success. The second aim was to examine whether the participants in the Strategy have collected information on the planning, implementation and results that will be needed for its final evaluation, to commence late in 1996.

1.1. ISSUES

The internal component of the mid-term review encompassed four issues.

Issue 1: *Coordination and collaboration*

> The review examined coordination efforts within Health Canada, between departments, between levels of governments and international linkages. Indicators include the existence of processes and structures for information-sharing; extent of planning and priority setting initiatives; the degree of information dissemination; and the identification of collaboration processes.

Issue 2: *Balance among NAS II Activities*

This issue deals with the appropriateness of activities, programming gaps and resource allocation within the Strategy. Indicators include evidence of inclusion in activities; common goals and priorities (such as reduced duplication); evidence of adaptability to changing circumstances; and differences between actual and budgeted expenditures.

Issue 3: *Implementation of NAS II*

This issue deals with the degree to which NAS II has been implemented and the activities are aligned with priorities established (i.e. "are they doing what they said they would do?"). The review examined the reliability of departmental monitoring structures, including any limitations to effective monitoring.

Issue 4: *Availability, quality, dissemination and use of information*

Indicators include the extent to which a component/organization maintains an inventory of on-going and completed information and research; the extent to which information/data gaps are identified and rectified; the extent of information dissemination activities, protocols, processes; the extent that information from partners is sought and used; and evidence on the use of epidemiological data to guide the Strategy and program activities.

1.2. LINES OF INQUIRY

Some issues can be explored using one line of inquiry while others are better suited for overlapping approaches. The results of the review are based on a combination of telephone and in-person interviews with selected Headquarters and regional staff, and reviews of program files, documents and data. Listed below are the rationales of the three methods of inquiry used to address the issues:

a) Interviews

This method obtained input from a cross-section of departmental managers and staff and other government officials responsible for funding and coordinating NAS II, including provincial and territorial governments. It sought their views and experiences with internal cooperation and coordination of the elements of the Strategy (i.e. sharing information, leadership), and to identify whether they felt that there are areas for improvement and changes required.

b) File reviews

These were conducted at both headquarters and in the regional offices visited. The objective of the file review was to identify the mechanisms for interface in the federal government, provincial governments, international linkages and non-governmental organizations (NGOs). Data gathered through these reviews were also used to augment and verify information obtained from officials.

c) Information review

The review examined files for management information and statistical/epidemiological) data, and posed questions to various participants to assess the usefulness of information and statistics generated and disseminated.

2. METHODOLOGY

2.1. INTERVIEWS WITH OFFICIALS

The following sections summarize the location, timeframe and number of interviews with headquarters, regional and provincial officials.

2.1.1. INTERVIEWS WITH HEADQUARTERS OFFICIALS ON-SITE

Interviews took place with 18 headquarters officials between August 11th and 29th, 1995. Table 1 shows the federal components of NAS II represented.

TABLE 1
INTERVIEWS WITH HEADQUARTERS OFFICIALS*

Organization/Program	Number
ACAP	1
ACTSU	1
AEPU	1
AIDS Secretariat	3
Bureau of Drug Research	1**
Bureau of Human Pres. Drugs	1
HPB - Div. of Epidemiology	3
HPB - LCDC	2
International Affairs Directorate	1***
Medical Research Council	1
MSB - First Nations and Inuit Health Services	1**
NHRDP	1
Corrections Canada	1
TOTAL	**18**

* The Bureau of Biologics was not included due to its participation in the Krever Commission.

** Denotes more than one respondent participating in the interview.

*** This area was added in response to information emerging from interviews.

2.1.2. REGIONAL TELEPHONE INTERVIEWS

From September 13th to 29th, the majority of telephone interviews were conducted with regional ACAP and MSB officials, provincial coordinators and epidemiologists. Remaining interviews were scheduled when practicable. Table 2 provides a summary of telephone interviews conducted by type and region.

TABLE 2
REGIONAL TELEPHONE INTERVIEWS

Region	ACAP	MSB	Prov. Coord.	Epidem.	Total
B.C.			1		1
Alberta	1	n.a.			1
Sask.	1*	n.a.	1	1	3
Manitoba	*	1			1
Ontario			1		1
Quebec	1	1	1	1	4
Atlantic					
YT/NWT	1	n.a.			1
TOTAL	4	2	4	2	12

* Note: One ACAP official represents both Manitoba and Saskatchewan.

2.2. REGIONAL VISITS

From September 20th to 30th, 1995, three regional on-site visits were made to meet with officials and to examine a sample of Health Canada Regional office files. The Pacific, Ontario and Atlantic regions were selected and the cities visited were Vancouver, Toronto, Halifax and St. John's, Newfoundland. Vancouver and Toronto are significant in terms of having two of Canada's largest HIV/AIDS communities.

TABLE 3
INTERVIEWS DURING REGIONAL VISITS

Region	ACAP	MSB	Prov. Coord.	Epidem.	Other	Total
Pacific	1	1	1	1		4[a]
Ontario	1	1	2	1	1	6[b]
Atlantic						
Nova Scotia	1	1	1	1	1	5[c]
Newfoundland			1	1	2	4[d]
TOTAL	3	3	5	4	4	19

a) Two interviews were scheduled in B.C. for provincial coordinators: I) Community program director; ii) Provincial AIDS Strategy official (conducted by telephone). One other coordinator was invited to participate but was unavailable.

b) Participants included in the ACAP interview were the ACAP Coordinator, Regional HPPB Director, and an HPPB officer who assists with ACAP. The "other" representative was the RDG.

c) Participants included in the epidemiologist interview were the provincial epidemiologist, and Director of the Labs. The "other" representative was the RDG. Two ACAP officials were present for the ACAP interview.

d) "Other" interviews included the ADM Health Programs, and Director of the Labs.

2.3. FILE REVIEW METHODOLOGY

Evidence was sought on the mandates, membership, activities, agendas and actual attendance at meetings of the committees and structures identified in the review. As well, the researchers examined reports emanating from these various coordinating mechanisms.

At the outset, file indexes were obtained from each organizational component prior to commencing on-site reviews. In most cases (except for Indian and Northern Services of MSB and the Division of HIV/AIDS Epidemiology of LCDC), these indexes were initially reviewed by the researcher and the project authority in order to familiarize the researcher with the types of file names that might contain the most relevant information.

The most critical information in a file was the date of documentation therein. Files and/or documents within files dated prior to May, 1993 were not included in the substantive review. File indices were examined to identify areas most likely to provide feedback on the effectiveness of coordination mechanisms. Although file indexes were used as a reference guide, the researcher scanned all available file titles on site and often reviewed the contents of "thicker" files.

Files were reviewed at:

The National AIDS Secretariat;
AIDS Education and Prevention Unit;
AIDS Community Action Program;
AIDS Care, Treatment and Support Unit;
National Health Research and Development Program of HPPB;
Division of HIV/AIDS Epidemiology;
Bureau of HIV/AIDS Laboratories and Research;
Bureau of Human Prescription Drugs of the Drugs Directorate; and
Indian and Northern Health Services of MSB.

Files in the ACAP and MSB regional offices were examined as part of the on-site visits. MRC and CSC files were not examined.

2.4. ASSESSING THE ADEQUACY OF INFORMATION FOR THE FINAL EVALUATION

To address the fourth issue, the review assessed the quality of management and statistical information produced by NAS II. Specifically, the research focused on the quality, timeliness and accuracy of the information disseminated to various organizations participating in the delivery of the Strategy. As well, key respondents were asked to comment on the usefulness and use of such information in their work. The purpose was to determine the adequacy of information generated by the Strategy for the final evaluation of the Strategy's impacts and effects.

DISCUSSION GUIDES

A. HEADQUARTERS

INTRODUCTION

The purpose of this discussion is to gather your views regarding the various coordination, implementation and information processes surrounding the National AIDS Strategy. Specifically, we are seeking your comments regarding the coordination and collaboration structures and activities of the various governmental agencies and the extent to which said structures and activities are effective and appropriate; the effectiveness of the Strategy's monitoring activities; and, the extent to which information available meets the needs of users. (Information will be sought from an overall Strategy, organizational, and international/federal/provincial perspective)

1. What tools and processes are in place to assist you in your coordination activities at the level of the overall Strategy, and at the level of your part of the Strategy? (Probe: How often does your organization meet with other NAS partners? With what organizations do you meet most frequently? Are these organizations appropriate given your mandate?)

2. Are these coordination processes adequate to accomplish the objectives intended? (e.g., planning, action plans, budgeting, monitoring, etc.) (Probe: what aspects of current structures are working as desirable?)

3. How do you go about monitoring the implementation of the NAS II? Do you believe these monitoring mechanisms and structures are adequate and appropriate? Is there anything that limits your ability to monitor the Strategy? (Strategy, unit perspective)

4. Are there any other monitoring and/or coordination mechanisms you believe should be considered to better assist you? How would you improve upon current processes?

5. Do you consider the mandate and objectives of the Strategy and your organization's role appropriate for achieving the results desired of the NAS generally? Do you believe your mandate and objectives should be re-assessed in any way?

6. Do you believe the current balance between research, care, education, and other activities is most appropriate? Why? Why not? (e.g., funding, priorities, programming...) If you believe that priorities should shift, from where should resources come?

7. What suggestions would you make to improve the effectiveness of the Strategy? Would you make any changes to improve your own component's effectiveness? (Probe: mandate, activities, coordination, responsibilities, areas of duplication, monitoring)

8. Are there any other comments you would like to make?

Re: DATA

This section is intended to generate greater detail regarding current data and management information. These questions should be asked of those with either a particular interest, or that are knowledgeable. Most importantly, time may be of the essence in an interview situation. Data questions could be asked under "monitoring".

1. Is the information generated by federal government agencies adequate and valid to assist you in supporting the Strategy? Are there adequate mechanisms in place to ensure the best quality information? (e.g., deaths attributed to AIDS, accurate diagnoses reflected, tracking of risk behaviours, maintenance of adequate HIV data on the front lines).

2. How do you use these data both externally in terms of sharing with partners, and internally in terms of setting and adjusting work priorities? Are these sharing arrangements optimal? How can these arrangements be improved?

3. Is the information that is generated delivered in a timely manner?

4. Are there any gaps you can identify in the information currently available? (i.e., Is the information useful to the various users? e.g., HIV and AIDS data).

5. What suggestions would you make to improve upon the quality of the information?

6. In the past, a number of discrepancies have been noted regarding the statistics circulated by the media and those reported by the federal government. How would you account for this? Is there any way to mitigate against these circumstances?

(Note: Key lines of questioning are: What is in place?, Does it work as desirable?, What is required to improve upon identified areas?)

B. HEALTH CANADA REGIONAL OFFICIALS

INTRODUCTION

The purpose of this discussion is to gather your views regarding the various coordination, implementation and information processes surrounding the National AIDS Strategy. Specifically, we are seeking your comments regarding the coordination and collaboration structures and activities of the various governmental agencies and non-governmental partners and the extent to which said structures and activities are effective and appropriate; the effectiveness of the Strategy's monitoring activities; and, the extent to which information available meets the needs of users. (Information will be sought from an overall Strategy, organizational, and international/ federal/provincial perspective)

1. What structures and processes do you use to coordinate your activities with other federal, provincial, and non-government participants? (Probe: How often does your organization meet with others involved in the Strategy? With whom do you meet most frequently?) What improvements, if any, might be desirable in coordinating activities of the players in the AIDS Strategy?

2. Are these coordination processes adequate to accomplish the objectives intended? (e.g., planning, priority setting, budgeting, monitoring, etc.) Are there other ways that would better allow you to coordinate and collaborate? (Strategy, unit perspective)

3. How do you go about monitoring the implementation of the NAS II? Do you believe these monitoring mechanisms and structures are adequate and appropriate? Is there anything that limits your ability to monitor the Strategy? (Strategy, unit perspective) What other ways can you monitor your activities more effectively?

4. From your perspective, is the Strategy doing what it was intended to do? What do you believe to be its strengths and weaknesses? (Probe: Appropriateness of mandate? What programs are adequately provided resources? Are there any striking deficiencies? How would you rectify these? From where would you suggest resources be taken to improve deficiencies?)

5. What information do you use most frequently? (e.g., budgets, statistical and/or research reports) From where do you obtain that information? Is it adequate given the nature of your work? Is dissemination adequate to serve the needs of your clients? (Probe: if possible, question about discrepancy in media reports)

6. What suggestions would you make to improve the implementation of the Strategy?

7. Are there any other comments you would like to make?

C. PROVINCIAL AIDS COORDINATORS

INTRODUCTION

The purpose of this discussion is to gather your views regarding the various coordination, implementation and information processes surrounding the National AIDS Strategy. Specifically, we are seeking your comments regarding the coordination and collaboration structures and activities of the various governmental agencies and non-governmental partners and the extent to which said structures and activities are effective and appropriate; the effectiveness of the Strategy's monitoring activities; and, the extent to which information available meets the needs of users. (Information will be sought from an overall Strategy, organizational, and international/federal/provincial perspective)

1. What structures and processes do you use to coordinate your activities with other federal, provincial, and non-government participants? (Probe: How often does your organization meet with others involved in the Strategy? With whom do you meet most frequently?) What improvements, if any, might be desirable in coordinating activities of the players in the AIDS Strategy?

2. From your perspective, is the Strategy doing what it was intended to do? What do you believe to be its strengths and weaknesses? (Probe: Appropriateness of mandate? What programs are adequately provided resources? Are there any striking deficiencies? How would you rectify these? From where would you suggest resources be taken to improve deficiencies?)

3. What information do you use most frequently? (e.g. budgets, statistical and/or research reports etc.) From where do you obtain that information? Is it adequate given the nature of your work? Is dissemination adequate to serve the needs of your clients? (Probe: if possible, question about discrepancy in media reports)

4. What suggestions would you make to improve the implementation of the Strategy?

5. Are there any other comments you would like to make?

D. PROVINCIAL EPIDEMIOLOGISTS

INTRODUCTION

The purpose of this discussion is to gather your views regarding the various coordination, implementation and information processes surrounding the National AIDS Strategy. Specifically, we are seeking your comments regarding the coordination and collaboration structures and activities of the various governmental agencies and non-governmental partners and the extent to which said structures and activities are effective and appropriate; the effectiveness of the Strategy's monitoring activities; and, the extent to which information available meets the needs of users. (Information will be sought from an overall Strategy, organizational, and international/federal/provincial perspective)

1. What structures and processes do you use to allow you to coordinate your activities with other federal, provincial, and non-government participants? (Probe: How often does your organization meet with others with whom you cooperate? With whom do you meet most frequently?)

2. From your perspective, is the Strategy doing what it was intended to do? What do you believe to be its strengths and weaknesses? (Probe: Appropriateness of mandate? What programs are adequately provided resources? Are there any striking deficiencies? How would you rectify these? From where would you suggest resources be taken to improve deficiencies?)

3. What information do you use most frequently? (e.g., budgets, statistical and/or research reports) From where do you obtain that information? Is it adequate given the nature of your work? Is dissemination adequate to serve the needs of your clients? (Probe: if possible, question about discrepancy in media reports)

4. Do you believe the sources of information you use regularly to be reliable and useful? Are the right data being produced? What is the demand for information produced by the Strategy? In your view, are these data used by other players in the AIDS field? (Probe: what use do they make of the data, e.g., realigning priorities, planning).

5. Do you believe that the information currently being generated enables us to monitor the evolution of the AIDS epidemic? Is there sufficient information available to allow us to assess the impacts of current program efforts?

6. Are there any general comments you would like to make regarding the implementation of the Strategy?

E. HEADQUARTERS - INTERNATIONAL FOCUS

1. What tools and processes are in place to assist the Department in coordinating its AIDS activities internationally? (Probe: How often does the Department meet to discuss issues of international significance? How often does it meet with other Canadian partners regarding AIDS issues? With what organizations does it meet? Are these organizations appropriate given your mandate and responsibilities?)

2. Are these coordination processes adequate to accomplish the objectives intended? (e.g. maintenance of Canadian profile, contribute to global HIV/AIDS efforts) (Probe: what aspects of current structures are working as desirable?)

3. How do you go about monitoring the implementation of the NAS II internationally? Do you believe these monitoring mechanisms and structures are adequate and appropriate? Is there anything that limits your ability to monitor the Strategy?

4. Are there any other monitoring and/or coordination mechanisms you believe should be considered to better assist our efforts internationally? How would you improve upon current processes?

5. Do you consider the mandate and objectives of the Strategy and the Department's role appropriate for achieving the results desired of the NAS generally? Do you believe the Department's mandate and objectives internationally should be re-assessed in any way?

6. What should be the Department's/ Canada's priority under the Strategy internationally? Are there any barriers that inhibit meeting these priorities?

7. What suggestions would you make to improve the effectiveness of the Strategy internationally?

8. Are there any other comments you would like to make?

APPENDIX B

CORRECTIONAL SERVICE OF CANADA HIV/AIDS MID-TERM REVIEW - TABLE OF CONTENTS

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APPENDIX C

METHODOLOGY - PANEL STUDY

1. INTRODUCTION

The mid-term review of the National AIDS Strategy Phase II (NAS II) includes the first wave of a panel study of non-governmental stakeholders. It was designed to obtain the views and perceptions of non-government stakeholders to supplement information from various government sources. The panel study focuses on the implementation, coordination and balance of the Strategy, and the information provided through the Strategy in terms of its quality, dissemination, and usefulness and use.

The primary purposes of this first wave of the panel study are: to provide feedback on the issues of interest noted above, and to provide **baseline information** on these and other issues related to the success of the Strategy. A second wave of the panel study (to be performed at the time of the final evaluation scheduled to begin in the fall of 1996) will obtain input from the same individuals on the same topics. The purpose is to track their experiences and perceptions of the Strategy's performance and success over time.

The panel study includes a cross-section of non-government stakeholders knowledgeable in the area of HIV/AIDS. Its composition has been designed to reflect the fact that the Strategy has a community-based focus, but involves a broad array of stakeholders. The diversity required for the panel composition was defined to include panellists from:

- local/community organizations
- national, provincial and regional non-governmental organizations
- specific targeted groups (e.g. Aboriginal communities)
- service providers
- advocacy groups
- professional organizations
- service and research organizations
- academia

2. METHODOLOGY

2.1. DESIGN

The design consists of completion of interviews with a cross-section of panel members knowledgeable about various activities related to HIV/AIDS in Canada. Their views were elicited at this point in time ("T1") based on a semi-structured questionnaire administered by telephone. The same panel members will be interviewed a second time ("T2") towards the end of NAS II and asked the same questions in order to document any shifts in views and the perceived responsiveness and continued relevance of the Strategy.

All panel members were asked the same questions in order to maximize the degree of consistency and comparability. Areas of questioning were intended to cover four basic areas of the Strategy: its implementation, coordination, balance and its provision of information.

2.2. PANEL SIZE AND MEMBER SELECTION

The size of the panel is 115 individuals. The panel is composed of a cross-section of knowledgeable individuals involved in HIV/AIDS related activities across Canada. These activities are varied, and include: front-line community-based care, treatment and support, education, various medical services, laboratory testing and research of various types.

It is recognized that most such individuals would be affiliated with one or more organizations related to their main type of activity. For instance, those involved in front line community-based treatment and support services would likely be associated with a local HIV/AIDS committee, and those doing various types of medically-oriented research would likely be associated with a hospital or university.

Because of this, panellists were typically recruited through such organizations. It is important to note, however, that panellists were approached as knowledgeable **individuals** regarding HIV/AIDS, and not as official spokespersons for an organization with which they are affiliated.

This approach to panellist selection is based on a recognition that organizations have other fora for the expression of views on NAS II, and a desire to encourage individual panellists to be candid by being able to express their personal views with the assurance of confidentiality. Thus, no remarks are attributed to individuals nor to organizations with which they are affiliated. The data analysis looks at the range of answers provided in terms of the total panel. It also examines organizational affiliation (e.g. hospital, community-based AIDS service organization). However, this was done only to see if there are differences in viewpoints among panellists involved in different types of activities that can be expected to be the focus in different types of organizational settings.

2.3. PANEL DISTRIBUTION

The distribution of panel members was designed to reflect certain key criteria to provide the desired cross-section of activities:

- Inclusion of a relatively high proportion of individuals affiliated with community-based service organizations doing much of the front-line work in education, care, support and treatment. The activities of these organizations and their approach, as noted, are a fundamental aspect of the Strategy.

- Inclusion of individuals affiliated with professional associations, including, insofar as possible, key national partners in the Strategy.

- Inclusion of a cross section of those involved in research.

- Inclusion of a cross section of those involved in the medical aspects of HIV/AIDS, whether clinical, laboratory or research oriented.

- Inclusion of those involved in corrections-related activities.

- Inclusion of those serving Aboriginals on reserves.

To achieve this cross-section the potential panellists were grouped into basic categories and numbers of total interviews to be completed within each category were assigned.

- "Group I" included various lists of names of individuals thought to be involved in community based activities. 55 interviews were to be completed from this group using a random sampling Strategy, plus up to six interviews with those affiliated with national partners in the Strategy.
- Those involved with Aboriginals on reserves were assigned 13 completed interviews (these are in addition to other community-based organizations in Group I that serve Aboriginals, but are not located on reserves).
- Those involved in corrections were assigned 8 completed interviews.
- "Group II" included various lists of names of those thought to be involved in providing professional activities related to HIV/AIDS. A total of 33 interviews were to be completed from this group.

Together these total the 115 panellists recruited for this study.

2.4. SAMPLING FRAMES AND SAMPLING STRATEGY

Lists were provided by Health Canada and Correctional Services Canada. These included contact names and names of organizations covering the four segments previously mentioned. As noted, for sampling purposes, the lists were divided into two broad groups. Group I included organizations or individuals whose activities relate to community-based activities. Group II included organizations or individuals involved in various professional activities and included, for instance, lists of physicians.

Group I

Panellists involved in community-based activities were assigned to Group I. This included 55 of 115 panellists as noted above. In addition, the six interviews to be completed with those affiliated with the five national partners and the Assembly of First Nations were assigned to Group I as were the interviews to be completed with those involved in Corrections (8 panellists) and those affiliated with Aboriginals on reserves (13 panellists). Together these totalled 82 of the 115 panellists.

Lists provided by Health Canada and Correctional Services Canada and others yielded a total of 952 possible contacts for Group I. Of this number, 143 were related to those affiliated with Aboriginals. These listings were treated as a sub-sample frame to ensure the inclusion of the desired number (13) of panellists related to Aboriginals on reserves. The 43 listings of those involved in corrections related activities were also treated as a sub sample to ensure inclusion of the desired number of panellists (8).

Group II

There were 816 possible contacts in Group II. Thirty-three of the completed interviews were allocated to this group.

2.5. SAMPLE SELECTION

Panellists for each category were chosen for the sample using a systematic sampling procedure. This procedure involved dividing the listing of potential panellists in the category by the desired number of completed interviews. This resulted in cells which each contained several names. A name was chosen randomly from each cell for inclusion in the panel. This procedure yielded the desired number of 115 contact names with the distribution noted above. Only 70 of the originally selected names were eventually reached and interviewed. The other 45 of those initially selected had to be replaced, sometimes with several successive names.

2.6. SAMPLE REPLACEMENT

Potential panellists had to be replaced for a variety of reasons:

- target person was unavailable
- name was a duplicate
- person was a federal or provincial government employee
- individual refused
- organization was no longer in existence
- individual or organization could not be located
- individual of interest within an organization could not be reached.

At least five telephone calls were made to an individual or organization before a replacement was chosen. When a replacement was required the next name in the cell was chosen. In cases where the cell was exhausted with no resulting completed interview, a new cell was randomly selected and the procedure was repeated. Careful records were kept of all attempts.

In the sub-group of those affiliated with corrections related organizations, a unique situation arose. After a number of attempts to contact certain individuals, it was decided, in conjunction with the client and Correctional Services Canada, that in the event that an individual who should be included on the panel is an inmate of a federal correctional institution, the next name in the cell would be chosen. This approach avoided the Privacy Act issues inherent in attempting to contact individuals in Corrections facilities, and also avoided possible duplication with input that can be provided by inmate committees under the Corrections and Conditional Release Act.

2.7. RECORD OF ATTEMPTS AND REPLACEMENTS

As stated earlier, several respondents had to be replaced for various reasons. The following is a breakdown of the number of replacements that occurred and reasons for replacement.

Reason for Replacement	Number replaced
Designated individual was ineligible - federal or provincial government employee	39
Unable to locate respondent or organization	28
Duplicate name	17
Unable to make contact with respondent (after at least five attempts)	11
Designated individual affiliated with National Partner	10
Respondent was unavailable	2
Refusals including:	
Respondent did not feel they knew enough about the issue to respond	2
Respondent wanted payment	1
Respondent no longer works in AIDS	1
No reason given	1
Desire to use other avenues	1
Organization has disbanded	1
Number was disconnected	1
Total Replacements	**115**

Coincidentally, it required 115 replacements as noted above, in order to complete the 45 panellist interviews called for in the evaluation design that were replacements from the original sample of 115.

3. PROFILE OF PANEL MEMBERSHIP

3.1. ORGANIZATIONAL SETTINGS

While the unit of analysis for the panel study is individuals, it was considered important to obtain basic data on the types of organizational settings in which these individuals work. This information helps demonstrate the cross-sectional nature of the HIV/AIDS related perspectives included in the panel.

Table 1 shows the distribution of panel study members by organizational affiliation.

TABLE 1
ORGANIZATIONAL AFFILIATIONS OF PANEL STUDY MEMBERS

Organizational Affiliation	Number
Community-based: ○ AIDS specific ○ Non-AIDS specific	 34 8
University/Foundations/Centres/Researchers	21
Associations (including "National Partners")	16
Hospitals	15
Aboriginal (on reserves)	13
Corrections-related	8
Total	**115**

The distribution reflects the sampling design, which was structured to provide a cross-section of specialties with a corresponding expected mix of organizational types (e.g. community-based organizations, hospitals, associations).

- More than one third (42 of 115) are located in community-based organizations serving local communities or specific populations at the community or regional level. A local AIDS committee would be an example. (NOTE: This is in addition to the 13 panellists in the sub-sample related to Aboriginals on reserve).

- 21 are located in universities, foundations, etc., including a few (3) who are independent researchers.

- "Associations" refers to national-level associations even though they may be "community-based" in their focus. Sixteen are affiliated with or employees of an association, including professional associations, national service organizations, etc. Also included are those affiliated with "national partners" in the NAS II Strategy such as, the Canadian AIDS Society.

- 15 participants are affiliated with hospitals.

- 13 panellists are with Aboriginal councils/bands, etc. located on reserves which receive funding from the Medical Services Branch (MSB) of Health Canada. (This number of panellists was determined as part of the panel design). In addition, there were other organizations in the Group I sample that were serving Aboriginals in urban settings.

- 8 panellists are involved in one aspect or another of corrections-related services, including inmate and related populations. Again, this sub-set of participants was part of the panel design.

3.2. GEOGRAPHICAL DISTRIBUTION

The distribution of completed interviews by region was as follows:

Atlantic (9), Quebec (28), Ontario (39), Prairies (23), Pacific and the Yukon and NWT (16).

3.3. FOCUS OF ACTIVITIES

Participants indicated the geographic/jurisdictional focus of their activities (e.g. local through to national, etc.) More than one response was permitted. Responses are shown in Table 2.

TABLE 2
GEOGRAPHICAL/JURISDICTIONAL FOCUS OF ACTIVITIES

		Organizational Type					
Focus of Activities	**Total Mentions**	**Comm. Based**	**Hospital**	**Assoc.**	**Univ./ Found**	**Aborig.**	**Corr.**
Local	57	25	3	4	8	10	7
Regional	43	20	8	3	4	2	6
Prov/Terr	35	10	10	5	4	2	4
National	38	5	5	12	11	2	3
Other	17	3	3	4	7	-	-
Number of panellists	N=115	N=42	N=15	N=16	N=21	N=13	N=8

Just under half of respondents say their organization is involved in activities at the local level. The highest proportions of these are among community-based organizations, Aboriginal organizations involved in HIV/AIDS activities and the sub-sample of those involved with persons in corrections-related organizations. The lowest proportions are among those based in hospitals, those affiliated with associations, and those with universities/foundations/centres or on their own.

About one third of participants said their organization's activities include efforts at the regional level (bigger than local but smaller than provincial). This includes relatively high proportions of community-based organizations, hospitals, and those involved in corrections.

About three in ten indicate their organization's activities include efforts at the provincial/territorial level. This includes about one third of the associations and more than half of the hospitals.

A similar proportion have a focus at the national level. This includes a high proportion of universities/foundations/centres and associations.

"Other" includes those whose work involves international dealings, and a few whose work had no geographic focus.

3.4. ACTIVITIES RELATED TO HIV/AIDS

All participants were asked to indicate which of several activities are conducted by their organization in response to HIV/AIDS. They also indicated the primary activities of their organization. The distributions are shown in Table 3 and 4. More than one response was permitted.

TABLE 3
ACTIVITIES CONDUCTED BY ORGANIZATIONAL TYPE IN RELATION TO HIV/AIDS

		Organizational Type					
Activity	**Total Mentions**	**Comm. Based**	**Hospital**	**Assoc.**	**Univ./ Found**	**Aborig.**	**Corr.**
Education	99	42	8	13	16	13	7
Coord efforts by others	77	34	11	12	10	5	5
Advocacy	75	38	9	9	10	4	5
Counselling	73	37	8	5	8	9	6
Non-medical services	54	33	4	3	7	2	5
Support/care for PHA's	51	29	7	5	5	3	2
Medical	28	5	7	3	7	4	2
Biomedical Research	24	1	9	2	12	0	0
Lab testing	22	3	9	2	6	2	0
Epid. work	22	2	10	1	8	0	1
Clinical Services	20	5	7	2	5	1	0
Clinical trials	18	1	10	0	7	0	0
Number of panellists	**115**	**42**	**15**	**16**	**21**	**13**	**8**

The most prevalent activities are education, followed by coordination of efforts by others, and advocacy. Next in rank are counselling, and "other non-medical services", followed by "support for persons providing care for persons having AIDS or PHA's.

All community-based organizations said they did education, and nearly all did advocacy and counselling. About three-quarters also said they coordinate efforts by others, provide non-medical services, and support for persons providing care for PHAs.

For universities, centres, foundations and a few independent respondents no longer affiliated but still active in the area, the more prevalent activities include education, biomedical research, coordination of efforts by others (N=10), advocacy, counselling, epidemiological work, non-medical services, clinical trials, and laboratory testing.

Among associations the more prevalent activities include education, coordination of efforts by others, and advocacy.

More prevalent activities by hospitals included coordination of efforts by others, epidemiological work, clinical trials, biomedical research, and laboratory testing. A majority also indicated doing advocacy, which could refer to the hospital itself or a specialized unit or service within it. Several also indicated involvement in other activities like education, counselling, and support for persons providing care for PHAs. Medical services, and clinical services were also mentioned.

Among the MSB supported Aboriginal organizations, all focus on education (13 of 13) and a majority do counselling.

Among the corrections-related sub-group, nearly all are involved in education and counselling. Most are also involved in advocacy, coordination of efforts by others, and non-medical services.

3.5. PRIMARY ORGANIZATIONAL ACTIVITIES RELATED TO HIV/AIDS

Respondents were asked to identify the main HIV/AIDS related activities of the organization with which they are affiliated. The primary activities identified and organizational types are shown in Table 4.

TABLE 4
PRIMARY ORGANIZATIONAL ACTIVITIES RELATED TO HIV/AIDS

		Organizational Type					
Activity	**Total**	**Comm. Based**	**Hospital**	**Assoc.**	**Univ./ Found**	**Aborig.**	**Corr.**
Education/ prevention	50	26	1	4	4	13	2
Care and Support	26	15	0	5	2	0	4
Medical research	18	0	7	1	10	0	0
Other medical including lab testing, clinical	13	1	7	3	2	0	0
Soc'l/economic research/policy	8	0	0	3	3	0	2
Number of panellists	**115**	**42**	**15**	**16**	**21**	**13**	**8**

Nearly half indicate the primary activities are education and prevention.

About a fifth indicate that care and support are the primary activities.

Of the remainder, 18 focus on medical research, 13 indicate their primary activities related to clinical treatment and testing, and 8 indicated the primary activity was non-medical research.

A number of respondents said that, in their organizational setting, a range of other services are provided in addition to the primary activities.

Primary/target population of activities

All participants were asked if there is a primary population to which the HIV/AIDS related activities are directed.

- 100 of 115 indicated there is (some mentioned more than one)
- 15 of 115 did not specify any target population

A range of target populations were identified. These include:

Persons having AIDS	30 mentions
Youth	14 mentions
Native communities	9 mentions
Intravenous drug users	9 mentions
Gay men	9 mentions
Prison inmates	8 mentions
The gay community	6 mentions
Women	6 mentions
Friends and family of PHA's	5 mentions
Caregivers	4 mentions
Ethnic communities	4 mentions
Bisexual men	3 mentions
Marginalized groups	3 mentions
Children	3 mentions

A variety of other target groups were mentioned by one or two respondents.

For those not identifying target populations it was typically because it was generic medical work. Therefore, out of 100 organizations who indicated that they have one or more primary populations to which their activities are directed, a total of about 125 mentions were made of target populations. This indicates that most activities are focused, and that a broad range of target groups are being served.

PANEL MEMBER'S RESPONSIBILITIES

All panel members were asked to indicate their own primary area of responsibility in response to HIV/AIDS. Some provided more than one response and some did not respond. The answers are shown in Table 5.

TABLE 5
PANELLIST'S PRIMARY RESPONSIBILITY IN RESPONSE TO HIV/AIDS

		Organizational Setting of Panellists					
Primary Response	**Total Mention**	**Comm. Based**	**Hospital**	**Assoc.**	**Univ./ Found**	**Aborig.**	**Corr.**
Education	41	21	3	0	4	9	4
Management/ administration	31	17	3	5	5	1	0
Research	19	0	7	1	8	0	3
Coordination/ facilitation	18	8	1	3	1	5	0
Advocacy	11	8	0	2	1	0	0
Support	5	4	0	0	0	0	1
Program development	5	3	0	0	0	1	1
Fund raising	5	3	0	1	0	1	0
Total Panellists	N=115	N=42	N=15	N=16	N=21	N=13	N=8

Education was mentioned most often as the panel member's primary responsibility. Management/administration was mentioned by the second greatest number. This partially reflects the fact that interviews in many cases were with the executive director (or equivalent) in a cross-section of organizational settings.

Research ranked third, followed by coordination/facilitation. The latter may overlap to some degree with management/administration. Advocacy was mentioned as a primary activity by 11 panellists. A number of other primary activities were mentioned, but none by more than 5 panellists each.

PROVISION OF DIRECT SERVICES

Panel members were asked if they personally provided direct services to persons having HIV/AIDS. The results were available for most participants and are shown in Table 6

TABLE 6
PANELLISTS PROVIDING DIRECT SERVICES TO PEOPLE WITH HIV/AIDS

	Organizational Setting of Panellists						
Direct services provided	**Total**	**Comm. Based**	**Hospital**	**Assoc.**	**Univ./ Found**	**Aborig.**	**Corr.**
Yes	46	20	6	5	8	2	5
No	47	10	5	9	9	11	3
Missing data	22	12	4	2	4	-	-
Number of Panellists	N=115	N=42	N=15	N=16	N=21	N=13	N=8

About four in ten said they do provide direct services. For community-based organization panellists (including the corrections-related sample) the services focused on education, counselling, referrals and support. For those affiliated with hospitals and universities the services focused on medical research, medical (primary care) services and social research.

The above data should not be taken as representative of the organizational settings listed nor their primary activities, etc. However, they do show a wide range of organizational settings and activity areas for panel members. This cross-section including the use of random sampling, helps to demonstrate the likelihood of a full range of perspectives being included among panellists.